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WOMEN LIVING WITH CROHN'S DISEASE

by

M. Lynne Compton

**A Thesis submitted to
The Faculty of Graduate Studies and Research
Through the Faculty of Nursing
In Partial Fulfillment of the Requirements for
the Degree of Master of Science in Nursing at the
University of Windsor**

Windsor, Ontario, Canada

2002

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ABSTRACT

Crohn's disease (CD) is one of the conditions that is classified under inflammatory bowel disease. Crohn's disease is a chronic condition that is increasing in incidence in women. Four women were interviewed on three or four occasions over a two year period. All interviews were transcribed verbatim. The purpose of this grounded theory study was to provide an understanding of the experience of women living with Crohn's disease (CD). This study also verified, through the emergent fit mode, that Hernandez' theory of integration was useful in explaining the phases that women went through in learning to live with CD. The three phases of integration identified in this study were the having CD phase, turning point phase and science of one phase. This three-phase process involved the integration of the personal self that existed prior to the diagnosis of CD and the CD self, which emerged after diagnosis. The common problem was discovered to be the necessity of dealing with the two selves. Lifeways, or characteristic patterns of thinking or acting, were found in the first phase and the third phase that kept individuals in that particular phase. Having CD consisted of the lifeways of denying, normalizing, minimizing and personifying. The science of one phase consisted of the lifeways of tuning in and engaging others. Three women were found to be in the having CD phase and one was in the science of one phase. Although more research is required to explore and confirm the study findings, the theory of integration does have potential for use by the advanced practice nurse to improve the physical health and quality of life of individuals living with CD.

DEDICATION

To John,

This thesis is dedicated to my husband John, whose lived experience with ulcerative colitis inspired the concept for research into Crohn's disease.

Thank you for your support throughout the thesis years. I could not have finished without you. You have certainly proved your love.

This thesis is also dedicated to the participants of this study who readily shared their experience of living with Crohn's disease.

Lynne

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I would like to thank Cheri Hernandez for her patience and encouragement to persevere to completion of this thesis. Thank you for not letting me give up.

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Lynne Compton

Chatham, Ontario

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CHAPTER ONE

Introduction

Overview of Crohn's Disease

Inflammatory bowel disease (IBD), a diagnosis that consists of ulcerative colitis (UC) or Crohn's disease (CD), affects about 1% of Canadians (Crohn's and Colitis Foundation of Canada [CCFC], 1997). CD is a chronic condition that is increasing in incidence in Canada and is a disease that has a major physical, psychosocial, and economic impact on the individual. CD is characterized by unpredictable periods of remission and flare-up of symptoms. Symptoms include severe diarrhea, rectal bleeding, abdominal pain, weight loss, malnutrition, anemia, and weakness. Extra-intestinal manifestations that typically complicate CD are arthritis, skin disorders, and eye problems. CD also has psychosocial and economic ramifications influencing family life, work life, social life, and intimate life, all impacting on the overall quality of life of the individual.

Although much has been written about symptoms and complications of CD, little is known about the effect of these on the lives of those who have been diagnosed with CD. The purpose of this study is to examine the personal experience of women living with CD on a day-to-day basis.

Included in this chapter is a summary of the physiological and psychosocial impacts of CD on an individual. Following a brief discussion of Hernandez' (1991, 1995, 1996; Hernandez, Antone & Cornelius, 1999; Hernandez, Bradish, Laschinger, Rodger & Rybansky, 1997) theory of integration, a comparison of CD and diabetes will provide justification for the use of Hernandez' theory of integration as a beginning theoretical framework for this study. Finally, the significance of this study to nursing will be discussed.

Physiological Impact

The impact of CD on physical health is significant and pervasive. Symptoms typically

occur over a period of time before an individual seeks medical help. Treatment is aimed at reducing inflammatory symptoms to induce remission, but is not satisfactory in many cases (VanDeventer, Elson, & Fedorak, 1997). Treatment includes medication, nutrition, and surgical intervention. Medications used are very potent and have many side effects that can be as severe as the disease itself (Hanauer, 1996). There is no specific diet to date that has been effective for CD although the majority of patients with CD experience significant weight loss, anemia, lactose intolerance, vitamin, mineral and nutrient deficiencies that further compromise health (Gramlich, 1997).

Complications of CD are very common and may be directly related to disease activity in the bowel such as strictures leading to bowel obstruction, toxic megacolon, fissures and fistulas, particularly in the rectal area (Kurkiakos & Champion, 1993), or may be related to disorders commonly accompanying IBD such as arthritis, skin rashes, inflammation of the eyes, gallstones and sclerosing cholangitis, a deterioration of the liver (Feverly, 1999; Kurkiakos & Champion). These extra-intestinal effects may be present without active bowel symptoms and therefore, also impact on the individual's well-being.

Approximately 75% of people with CD will have surgery at some point, even though surgery does not cure CD (CCFC, 1997). Often bowel resection for CD results in an ostomy, which may be temporary or permanent. Surgery for CD relieves symptoms but the chance of recurrence is very high. To date, there is no cure for Crohn's disease and treatment is often aggressive with many side effects.

Economic Impact

Patients with CD have a very high rate of health service use, even those with inactive disease. The costs have been divided into direct and indirect costs (Feagan, 1999). Direct costs include health care service provided, such as inpatient and outpatient costs. Hay and Hay (1992)

stated that in a given year, a person with active CD might make nine visits to various physicians and two visits to hospitals for outpatient services, be hospitalized for twenty-six days and be incapacitated for forty-five days for an estimated annual cost of \$6,561 U.S. A more recent study estimated the average annual medical costs per patient with Crohn's disease in the U.S. to be about \$12,417 demonstrating that CD is associated with high cost (Feagan, Vreeland, Larson, & Bala, 2000). Feagan estimated that surgery and hospitalization account for 70% of the cost, medications for about 11%, diagnostic work-up and annual office visits for about 18% and treatment of extraintestinal complications is estimated to be 5.5%. Another U.S. study indicated that projected lifetime costs per patient ranged from \$39,906 to \$125,404 (Silverstein et al., 1999). Approximately 20% of patients generated 80% of the average costs associated with CD (Feagan). A minority of patients requires hospitalization, but those who do, have a higher utilization and a higher overall cost of care. There have been no studies done in Canada to estimate the exact cost of CD but these studies signify that CD has a substantial economic impact.

Indirect costs are those that affect the social, economic and physical well being of the patient. Indirect costs include absence from work, decreased earnings, premature death and all of the effects of reduced quality of life (Feagan, 1999). Although indirect costs are difficult to assess, it has been estimated that indirect costs would amount to about twice the direct costs (Blomqvist & Ekblom, 1997).

Psychosocial Impact

Continuous symptoms in those affected by CD result in negative effects on psychological as well as social functioning due to the complex and unpredictable nature of the disease (Vallis & Turnbull, 1996). Females, persons with greater disease severity, and those with lower education reportedly have more concerns about their disease (Martin, Leone, Castagliuolo, DiMario, & Naccarato, 1992). A patient's worries about CD can affect health status by decreasing well-being,

increasing anxiety and increasing psychological distress (Drossman et al., 1991; Turnbull, Vallis, Luyendyk, Tanton, & Schep, 1995). Increased stress may lead to decreased compliance with medical regimens resulting in symptom flare-ups or poorer clinical outcomes (Garrett, Brantley, Jones, & Tipton-McKnight, 1991).

Unfortunately, for people with CD, healthy behaviour does not always lead to good health. Patients with inflammatory bowel disease including CD, even those who are relatively well, have described their quality of life as fair to poor despite excellent medical and surgical management (Botoman, Bonner, & Botoman, 1998; Irvine et al., 1994; Irvine, Feagan, & Wong, 1996; Maunder, Cohen, McLeod, & Greenberg, 1995; Yazdanpanah et al., 1997). The connection between CD flare-ups, life satisfaction, and daily stress has been well documented in the literature (Garrett et al., 1991; Greene, Blanchard, & Wan, 1994; Kinash, Fischer, Lukie, & Carr, 1993; Love, Irvine, & Fedorak, 1992; Milne, Joachim, & Neidhart, 1985).

Depression is common but under-recognized and under-treated in patients with CD especially during active disease (Dudley-Brown, 1996; Helzer, Chammas, Norland, Stillings, & Alpers, 1984; Kinash et al., 1993; Robertson, Ray, Diamond, & Edwards, 1989). It is not known if depression precedes CD, or if unrelenting symptoms over a period of time result in eventual depression (Ramchandani, Schindler, & Katz, 1994). Research results of twenty years ago indicated that patients with CD had a higher incidence of suicide but no recent studies have been done to determine if this trend has continued (Drossman et al., 2000). There is no evidence to support that psychotherapy affects the clinical course of CD but stress management has been found to be beneficial (Enck & Schaffer, 1996).

Although much has been written about psychosocial effects of chronic illness over the past twenty years, (Burckhardt, 1987; Charmaz, 1990; Dluhy, 1995; Eitel, Hatchett, Friend, Griffin, & Wadhwa, 1995; Kline-Leidy, Ozbolt, & Swain, 1990; Lambert & Lambert, 1987;

Lindsey, 1997; Vallis & Turnbull, 1996), an in-depth investigation of the psychosocial impact of CD from the patient's perspective has not been done. This is a major gap in the literature given that CD is often diagnosed at a young age when work, family, and social lives are the most demanding. Therefore, a study, that investigates the issues that women with CD are dealing with each day, would be very useful to health care practitioners.

Author's Interest in Crohn's Disease

Caring for clients who have IBD generated the author's interest in CD. Women with CD were particularly challenging to work with. The incidence of CD in women is on the rise (Bernstein, 1997) and women typically report more concerns about the impact of CD on their lives (Drossman et al., 1991). The author observed that women with CD appeared to have a much more difficult time coping with their illness than men and were labelled as noncompliant by health care professionals when they required frequent medical attention or when symptoms did not respond well to treatment. Interest in studying women with CD was further stimulated by the lack of research describing the patient's personal perspective of living with CD.

The studies specifically related to women and CD focused primarily on reproductive problems and other sexual health issues (Giese & Terrell, 1995; Gloeckner, 1984; Golis, 1996; Wilson, 1995). No studies were found to explore the in-depth experience of women living with CD day-to-day. Given the increasing incidence of disease in women, and the potential devastating effects of the disease over a long period of time, greater attention by health care professionals to the concerns of women with CD is warranted. Therefore, the purpose of this grounded theory study was to explore the personal meaning of CD by eliciting information from women living with CD on a day-to-day basis.

This study involved comprehensive interviews with women diagnosed with CD to get at their experience of living with CD. This study also explored the relevance of Hernandez' (1991,

1995, 1996; Hernandez, Antone & Cornelius, 1999; Hernandez, Bradish, Laschinger, Rodger & Rybansky, 1997) theory of integration to clients with CD. The theory of integration was developed through grounded theory research with clients who had Type 1 diabetes and extended to those with Type 2 diabetes. However, CD is a chronic disease with similar impacts as diabetes on an individual, such as the pervasive symptomatology, life-threatening complications and major psychosocial ramifications and both require ongoing and complex decision making in self-care to promote quality of life. Therefore, investigation of the theory of integration and its relevance to CD is reasonable. The findings of such a study are important to nursing in order to provide nursing care that is congruent with the experience of living with CD and, therefore, should promote better client outcomes.

Theoretical Framework: Theory of Integration

The theory of integration was developed by Hernandez (1991) through grounded theory research, to explain the experience of living with Type 1 diabetes and later confirmed in those with Type 2 diabetes (Hernandez et al., 1999). Integration has been defined by Hernandez (1991) as "an ongoing process in which the two selves (diabetic and personal) more fully merge to create an individual who is healthy, both mentally and physically. The unification of the selves is manifested in the person's way of thinking, being and acting (including verbalization)" (p. 19). The personal self is the self that existed prior to diagnosis of diabetes. The diabetic self is the new entity that emerges upon diagnosis. The personal self and diabetic self gradually merge over time through a three-phase process of integration. Lifeways, "the characteristic patterns of thought or action used without conscious knowledge" (Hernandez, p. 99), used by individuals can help or hinder integration of the two selves. Lifeway strategies could be physical, emotional, or cognitive (Hernandez, 1996). Metaphors, overriding lifeways that characterize the lives of the individual, can also inhibit or facilitate integration. Active metaphors assist with change towards integration while passive

metaphors delay movement towards integration (Hernandez, 1996). Integration increases as the person moves through the phases.

The theory of integration includes three phases: having diabetes, the turning point, and the science of one. The first phase, called having diabetes, is characterized by inadequate knowledge about diabetes, and a disinterest in the disease, as well as a preoccupation with being normal or as one was before diagnosis. The individual would do the things that had to be done for the diabetes such as giving insulin injections and then would get on with life forgetting about the disease or at least relegating it to the background. Three major lifeways have been identified that kept the person in the first phase including denying, minimizing, and normalizing (Hernandez et al., 1999). The person who is denying might omit taking oral hypoglycemics, while the person who is minimizing would downplay the impact of diabetes, and the person who is normalizing would continue to live as prior to the diagnosis of diabetes. Passive metaphors such as "carrying on" or "being too busy" for diabetes were also identified that kept individuals in this first phase. One conflict that arises in phase one is the issue of who owns the disease. Ownership of the disease is usually by the health care professional (Hernandez, 1991). Another conflict that arises is the decision to tell or not to tell others about their diabetes. This conflict may exist for many years and most individuals limit the number of people they tell about their diabetes. Phase 1 typically lasts for at least three years but can last much longer, perhaps forever. The first phase ends when the individual can no longer deny, diminish, or ignore the implications of the diabetes (Hernandez, 1996).

The second phase, called the turning point begins when one or more significant life events force the individual to reassess and rethink life with diabetes. The precipitating event can be physiological, such as a severe episode of hypoglycemia, or a psychological event, such as referral to a new endocrinologist who begins to make major changes in the diabetic regimen, or may be a

combination of events (Hernandez et al., 1999). The focus in this phase is on the diabetes. The individual begins to take an interest in learning about diabetes and there is more involvement with self-care and decision-making. It is not known how long this phase can last. Some individuals may remain in this phase for some time before returning to phase one or moving on to phase three.

The third and last phase involves a gradual focus on living but not to the detriment of the diabetes. Hernandez (1996) calls this the science of one, because it involves "the ongoing incremental process of building a unique, personalized and exact science of living with diabetes" (p 46). The individual learns to tune into body cues and to use the knowledge from this heightened sensitivity to respond to the body's needs. The individual takes ownership of the diabetes and makes decisions related to all facets of the disease. The individual develops a deep understanding of his/her diabetes and has learned the actions to take to stay well. This phase involves experimentation and trial and error learning about diabetes. Individuals may even be skeptical of information given by health care providers as experience with their diabetes demonstrates that the advice given does not work in their particular cases. During this phase, the individual becomes the expert in diabetes as he/she learns to interpret and respond to bodily cues that occur while living life according to lifestyle needs and preferences. Several lifeways are used resulting in the facilitation or inhibition of the integration between the personal self and the diabetic self. Lifeways can be physical lifeways such as exercise, cognitive lifeways such as positive thinking, or emotional lifeways such as focusing on feelings. Each individual with diabetes had a unique science of one known only to self. Because participants felt they were the experts in their own diabetes, they desired a collaborative alliance relationship with health care providers.

The theory of integration is a new theoretical framework that has been developed and applied only in diabetes. Hernandez (1996) encouraged further research in other client populations to determine if the existence of a similar integration process exists in other chronic illnesses. This

study was designed to discover if the theory of integration has any relevance to the experience of women with CD. The many similarities between diabetes and Crohn's disease such as the chronicity, daily regimens, and debilitating complications warranted the investigation of the use of the theory of integration in women with CD.

Significance of the Study

Although much has been written about the impact of CD on physical health and the lifestyle adjustments required, little is known about the individual's experience of living with CD. There has been no research about the experience of women living with Crohn's disease. This is the first study that involved intensive interviews of women with CD to determine what living with CD is like. CD is increasing in women, therefore, an in-depth study will be useful to other women with CD, who may find that the experience described, fits their experience also; this could lead to improved outlook knowing that they are not alone. Studies did indicate that knowing more about CD was associated with greater sense of control and better psychosocial adjustment on the part of the client (Drossman et al., 1991, Martin et al., 1992).

Chronic illness is increasing as people live longer and there is a growing recognition of the need to shift decision-making for health care needs to the client. It is evident that more research should be conducted to determine which interventions patients would find more helpful from health care professionals, especially in light of Hernandez' (1995) findings, that advice from health care professionals is often perceived as inaccurate or unhelpful. Hernandez (1991) has found that patients prefer a collaborative alliance relationship with health care providers where each is a co-expert in dealing with chronic illness such as diabetes.

This study describing the unique experience of women will give the advanced practice nurse the opportunity to use new data to improve practice and to interact more collaboratively with these clients. This study looked at the patient's perspective and has discovered some very

important information to share with other health care providers about the needs of women with CD. This study will also promote the development of a realistic, outcomes-oriented plan for optimum care of these women and their families.

CHAPTER TWO

Review of the Literature

The literature on CD is prolific but authors have focused on particular physiological or psychosocial impacts of CD. Articles specific to women have mostly been limited to pregnancy and fertility issues. Most of what has been written has been from the perspective of the health care professionals or researchers in the fields of behavioural sciences, medicine, nursing, and psychology. The literature on CD included both theoretical and research articles. These articles have been summarized according to two broad categories, biological and psychosocial.

Biological Research

Incidence, Prevalence, and Cause of CD

Canada has one of the highest prevalences of CD in the world (CCFC, 1997). CD is found primarily in highly industrialized regions (Persson et al., 1996). The incidence of CD in Canada was found to be highest in those aged 30 to 39 years of age and was 35% higher in women (Bernstein, 1997; Freeman, 2001). The Crohn's and Colitis Foundation of America estimated that the incidence of CD in the United States is 1.2 to 15 cases per 100,000 population (Lewis, 1999). No research has been conducted to determine the exact percentage of the population affected by CD in Canada, especially those with mild disease, but it has been estimated that about 250,000 Canadians or roughly 1% of the total population have inflammatory bowel disease (CCFC). Findings by Bernstein indicated that not only is the rate of Crohn's disease higher than previously thought but it is also climbing at an alarming rate.

Although the exact cause of Crohn's disease is unknown, there are strong indications that it is multifactorial, involving genetic and environmental factors that result in an inflammatory immunologic response (Russel et al., 1997). Researchers have offered a wide variety of theories of possible causative factors for CD including genetic predisposition (Bernstein, 1997; Meucci,

Vecchi, & Torgano, 1992), autoimmune factors (Chadwick, 1992; Croitoru, Wong, & Baca-Estrada, 1996; Dayan, Chu, Londei, Rapport, & Feldman, 1993; Eisenbarth, 1996; Fiocchi, 1997; MacDermott, 1994; Nassif, Longo, Mazuki, Vernava, & Kaminski, 1996), dietary factors (Gramlich, 1997; Kreidie, 1998), infectious agents (Braun et al., 1996; Elson et al., 1994; Gitnick, 1992; James, 1987), environmental toxins (Bernstein, 1997) and ability to cope with stress (Garrett et al., 1991; Greene et al., 1994; Milne et al., 1985). Research is ongoing in the search for a cause for CD that would help to point the way to a cure.

Some of the more recent research initiatives have explored contributing factors associated with diet such as a proposed allergy to milk, wheat or a reaction to margarine and refined sugar. It has been suggested in some recent studies, that living in increasingly hygienic environments results in the failure to acquire parasites normally found in the bowel, which may predispose individuals to develop CD (Elliott, Urban, Argo, & Weinstock, 2000). While a cause has not been identified, research has led to the development of improved treatments.

Signs, Symptoms and Treatment of CD

The literature showed that CD has a major physical impact on all body systems and requires many complex treatment modalities. Therefore, CD has a pervasive impact on the individual's lifestyle and physical well-being. The advances of the past century have improved treatment and reduced complications but until a cause is determined for CD, treatment will continue to be palliative and supportive (Kirsner, 1998). Several hundred meta-analyses or descriptive overviews regarding treatment of CD have been published. Theoretical articles about CD discussed signs and symptoms (Ogorek & Fisher, 1994), drug and therapeutic management (Botoman et al., 1998; Guyatt et al., 1989; Hanauer, 1996; Hanauer & Meyers, 1997; Jones, Gallacher, Lobo, & Axon, 1993; Kornbluth, Marion, Salomon, & Janowitz, 1997; Quinn, Binion, & Connors, 1994; Sutherland, 1997; Thomson, 1996; VanDeventer et al., 1997), surgical

management (Cohen, 1996; Kosinski & Welton, 1998), pathology (Cottone, Cipolla, & Rosselli, 1995; Meddings, 1997, Thomson, 1996), the physical effects on various age groups from children to elderly (Aideyan & Smith, 1996; Ferguson & Sedgwick, 1994; Fleischer, Grimm, & Friedman, 1994; Justincich & Hyams, 1994; Pelletier, 1995), the complications (Kurkiakos & Champion, 1993) and extra-intestinal conditions associated with CD (Andreassen, Rungby, Dahlerup, & Mosekilde, 1997)

Research on CD has been largely quantitative and has been written from a health care professional's perspective. There have been a multitude of publications written about nutritional management (Fukuda, Kosaka, Okui, Hirakawa & Shimoyama, 1995), medication, and clinical drug trials (Hanauer & Meyers, 1997; Lowry & Sandborn, 1999; Song, Vadheim, Snape, & Heiner, 1995; Thomson, 1996; VanDeventer et al., 1997; Whiting, Lau, Kupelnick, & Chalmers, 1995). Research on the treatment for CD has focused on nutritional management, medications, and surgery.

The maintenance of nutritional status in patients with CD has been crucial, but somewhat frustrating for both patients and their physicians. Patients, over the years, have been placed on high fibre, low fibre, gluten free, low fat, low carbohydrate or lactose free diets with mixed results (Kirsner, 1998). To date, there is no specific diet for CD and diets today are aimed at improving overall nutritional status. However, it is very difficult for patients to maintain a balanced diet when feeling nauseated and when eating often results in the need to eliminate immediately after. Elemental protein and calorie supplements are not very palatable. Hospitalization of patients with CD for intravenous therapy is common due to dehydration or malnourishment.

Medications used currently for CD include corticosteroids, aminosalicylates, antibiotics, and immunosuppressive drugs. Results of drug therapy have varied from patient to patient and there is no single drug that is effective in managing the symptoms of CD (Rampton, 1999). The

side effects of the medications make it very difficult for patients to continue taking the medication on a long-term basis especially when they are in remission. The medical treatment of CD has not been very effective. Recent research interest has placed Remicade, a new experimental drug used exclusively for CD, in the research spotlight with very promising results (Lewis, 1999, Nikolaus et al., 2000; Rampton). There has been a surge of interest by researchers to search for new treatment options such as anti-inflammatory drugs and antitumor necrosis factor to block the immune response (Bayless et al., 1996; Panacione & Sandborn, 1999).

The efficacy of diagnostic studies or therapies including surgery has also been described in biological research (Cottone et al., 1994; Kosinski & Welton, 1998; Yazdanpanah et al., 1997). It can be safely said that most patients with CD will have surgery at some point. Surgery is not curative and there is a high incidence of recurrence of CD after intestinal resection. Many patients with CD, including those interviewed in this study, have had an appendectomy. One of the symptoms of CD is abdominal pain in the right lower quadrant at the ileoceccal valve. This is also the site of the appendix. Interestingly, studies have shown that appendectomy is associated with an increased risk of CD but researchers explain that since most appendectomies were performed close to the time of diagnosis of CD, the surgery was likely a result of yet undiagnosed CD (Koutroubakis et al., 1998; Russel et al., 1997; Sandler, 1998).

Smoking has been shown to worsen the clinical course of CD and has been another area of current research interest (Cottone et al., 1994; Cottone & DiMitri, 1999; Meddings, 1997; Rampton, 1999). An association has been suggested between the increase in women with CD and the increase of smoking in women at large.

Studies have shown that patients with CD have a high mortality rate from gastrointestinal complications such as severe liver disease, colon cancer and bowel perforation (Ekbom, Helmick, Zack, Holmberg & Adami, 1992; Persson et al., 1996). Mortality from CD was more common in

women but mortality rate has also declined over the years as a result of improved treatments.

Current therapy for CD has improved and progressed over the years but remains supportive rather than curative (Kirsner, 1998). Advances include improved treatment of complications, control of inflammation, newer anti-inflammatory agents with less side effects, better nutritional support and refinement of surgical procedures (Kirsner). CD has such a significant and pervasive impact on an individual's physical well being that knowledge of the effects of this impact on daily life is important information for nurses and other health care professionals who care for these patients.

Psychosocial Research

The physical effects of CD eventually affect the psychosocial well-being of the individual because of the chronic symptoms and the unpredictability of flare-ups. Researchers in the behavioural sciences and other disciplines have investigated many of these psychosocial effects of CD but findings have been from the perspective of the researcher. A summary of the psychosocial research includes discussion about the possible link of flare-ups to stress and personality traits, coping behaviours and quality of life issues, and finally psychotherapy. Following is a brief summary of findings of psychosocial research.

Stress and Personality Traits

Some studies have attempted to link stress with exacerbation of symptoms in CD. One prospective study of 10 subjects, four male and six females, with an average age of 41 years, found that daily stress has a greater impact on symptoms than major life events (Garrett et al., 1991). Similarly, a study of 11 patients with IBD, six of whom had CD, indicated that the more severe the stress on any one day or during any one month, the more severe the IBD activity at that same day or same month (Greene et al., 1994). It can be concluded that daily stress can contribute to flare-up of symptoms.

One prospective study followed 32 patients, 24 with CD, for two years to determine whether depressed mood or life events are associated with exacerbations of symptoms (North, Alpers, Helzer, Spitznagel, & Clouse, 1991). Findings indicated that while the mood of patients changed with flare-up of symptoms, there was no evidence that worsening mood precipitated flare-ups. Robertson et al. (1989) found that neuroticism and introversion were more common among patients with IBD including CD than for the general population, but they found low prevalence of anxiety and depression except in those with active disease. These studies indicate that depressed mood is likely a result of flare-ups rather than a cause of flare-ups.

Conversely, another study followed 174 women suffering from a variety of gastrointestinal disorders including CD and determined that those who tended to catastrophize, or who held pessimistic views about their illness tended to have poorer health outcomes (Drossman et al., 2000). The researchers posited that treatments like cognitive behaviour therapy would benefit these patients by helping them to replace maladaptive perceptions with more realistic ones but no intervention studies have been conducted to indicate whether cognitive therapy reduces gastrointestinal symptoms. Some literature has shown that patients with CD report more psychosocial disturbance than those with ulcerative colitis but neither group showed significant psychopathology (Dudley-Brown, 1996; Greene et al., 1994).

The literature has shown conflicting results in attempting to link CD to a psychiatric cause. Helzer et al. (1984) showed that a significantly higher number of patients with CD had a diagnosis of depression but found no other psychiatric illness. The authors also indicated that depression in patients with CD was under-recognized and under-treated and recommended the concomitant treatment of depression along with the physical symptoms of CD. Some studies have shown that the incidence of anxiety, panic, and depressive disorders are significantly higher in patients with CD than in controls (Ramchandani et al., 1994). The same authors also pointed out

that the increased association of psychiatric disorders might be a secondary effect for CD patients who typically have more symptoms and poorer prognosis than patients with other gastrointestinal disorders. Some authors have stated that the complex relationship between emotional and physical symptoms is yet to be determined (Dudley-Brown, 1996; Greene et al., 1994, Helzer et al., Ramchandani et al.). Ramchandani et al. proposed that the most successful approach to illnesses such as CD requires attention to psychiatric co-morbidity, effective adaptation to illness and positive patient-physician relationships.

There has been great interest in the behavioural psychology field over the last thirty years about the behaviour profile or personality traits of the patient with IBD including CD (Enck & Schaffer, 1996; Garcia, Fernandez & Sanchez, 1994; Robertson et al., 1989; Walker, Gelfand, Gelfand, & Katon, 1995). Alexithymia is a personality type that has been linked to individuals with psychosomatic illnesses and therefore with IBD. Alexithymia has been defined. as “the cluster of cognitive and affective characteristics including difficulty identifying and communicating subjective feelings, a restricted imaginative life and a concrete and reality-oriented style of thinking” (Porcelli, Zaka, Leoci, Centozone, & Taylor, 1995, p. 49). This repressive coping style keeps thoughts and feelings from surfacing into consciousness. Alexithymic individuals reportedly have high levels of negative emotion but have difficulty identifying and verbally expressing feelings. One study investigated the prevalence of alexithymia in a group of 112 IBD patients, 23 with CD, and compared results to 112 normal subjects matched for gender, age, and education (Porcelli, et al.). Results supported a moderate association between alexithymia and IBD compared to the control group, but the authors also pointed out that no firm conclusions could be drawn as to whether alexithymia occurred before or after the diagnosis of IBD.

Another study examined the relationships between alexithymia, emotional control, and quality of life in 74 patients with IBD over a one-year period (Verissimo, Mota-Cardoso, &

Taylor, 1998). Forty-nine of these patients had CD and, of those with CD, 15 were men, while 34 were women. Patients who scored with high degrees of alexithymia were found to have a perception of a lower quality of life and also reported more bowel and systemic symptoms and worse emotional functioning. Alexithymia did not influence the patient's social functioning of attending school or work or social engagements. Patients with the least alexithymia, and therefore more aware of their subjective feelings, reportedly enjoyed a higher quality of life. Although research has demonstrated that the alexithymic personality is more common in individuals with CD, not all those with CD have this trait. Despite 50 years of research, a disease-specific personality for CD has not been identified (Enck & Schaffer, 1996). It has been impossible to determine if an alexythymic personality type existed prior to CD, or if the chronic effects of CD over time caused alexythymic traits to emerge.

It is well established that stress can worsen the symptoms of CD because physical and emotional health are inextricably linked but an improved outlook could improve physical symptoms and symptoms of depression that result from living with CD. This study investigated the physical and emotional health experienced by women living with CD every day.

Coping and Quality of Life

Quality of life has been investigated with tools specifically designed for patients with IBD. These instruments measured functional, social and emotional dimensions of CD, and disease severity, as well as satisfaction with treatment (Irvine et al., 1994; Irvine et al., 1996). Patients' perceptions about their quality of life enhanced or hindered response to illness, their feelings of control over symptoms as well as adherence to prescribed treatment. Ramchandani et al., (1994) stated that that an effective patient-physician relationship is essential and treatment should include recognizing the patients' needs as well as their characteristics ways of functioning in order to influence collaboration and decrease distorted beliefs. For the person with CD, quality of life is

enhanced when feelings were supported by physicians and significant others (Ramchandani et al.).

MacPhee, Hoffenberg and Feranchek (1997) studied the responses of thirty adolescent/parent pairs to assess the adolescents' adjustment to recent onset of IBD. Findings indicated that the adolescents relied more on their parents' coping skills than their own or their peers. This has significance for behavioural therapy for those with CD who are diagnosed early in life, and confirms that CD affects the whole family dynamics. Perhaps the coping skills of family members of CD patients also affect how adolescents cope with their own symptoms.

In a descriptive survey, the coping behaviours, personality, and mood characteristics of 150 patients with IBD were examined (Kinash et al., 1993). Eighty-eight patients had CD and 48% of the sample was female. When clients were faced with problems in daily living, they reported that their coping style was one which focused on finding solutions to the problem rather than trying to relieve the distress accompanying the problem. The most frequently used coping strategies were trying to maintain control over the situation, examining the problem objectively and finding out more about the situation. The lowest ranked strategies were taking drugs, using meditation, yoga, or biofeedback, blaming others, letting someone else solve the problem and drinking alcohol. More than 80% reported they were satisfied with the way they were coping and with life in general. In this study, the IBD patients scored in the normal range on the depression inventory overall while the CD subgroup scored in the mild depression range. Studies such as these indicate that the coping skills of patients with CD have been found to be effective and realistic which refute beliefs that CD is a psychosomatic illness.

Psychotherapy

Psychotherapy and psychoanalysis were used as major approaches to patients with inflammatory bowel disease during the 1930s to the 1950s (Kirsner, 1998). Psychotherapy continues to be used today with mixed results, but there is no evidence to support conclusively

that psychotherapy affects the clinical course of CD (Enck & Schaffer, 1996). An analysis of patients receiving drug treatment alone or patients receiving drug treatment in addition to psychotherapy failed to prove any significant differences in clinical outcomes of CD (Jantschek et al., 1998).

Interest in the role of psychological factors in CD has flourished over the years. Study results have shown that patients with CD have a higher incidence of depression and a predilection to alexithymia. Despite ongoing research, it has been impossible to determine so far whether individuals with CD have an innate depressive trait predisposing them to depression or whether the unrelenting symptoms of chronic illness over time cause the individual to slip into a depressive state. But studies have led to possible treatment suggestions for patients with CD such as stress management, cognitive behavioural therapy for those who have pessimistic outlooks, the inclusion of significant others in strengthening coping skills, the early recognition and treatment of depression and the need for an effective patient–physician relationship. What has not been studied is the personal experience of living with CD day to day.

Research About Lived Experience of CD

Although there have been many publications about CD, few researchers have investigated the in-depth subjective experience of the person living with this illness. Only one publication by an Australian nurse discussed living with CD (Shorten, 1995). The author described what it was like to live with CD from her own personal experience with the disease. She described the reluctance to go far from home in order to avoid the anxiety associated with the unpredictable, sudden urge of diarrhea with no bathroom in sight. The main focus of the article was how nurses could best help patients with CD. Shorten suggested the following strategies for nurses to consider when caring for patients with CD; odour control by making air fresheners available and privacy by retrieving specimens promptly and ensuring access and proximity to a washroom. Another area

for improvement suggested by Shorten was in regards to elemental diets and how to make these more palatable by adding flavoured toppings or keeping the products refrigerated and avoiding derogatory comments about the taste. Finally, Shorten asked nurses to treat CD patients with dignity and commented that, as a recipient of hospital care, this had not been her experience.

Two studies were found that described the experiences of people living with ulcerative colitis (UC), another inflammatory bowel disease with similar signs and symptoms. Given the many similarities between CD and UC, it is very possible that the findings of these two studies may have relevance to clients with CD.

A phenomenological study described adults' experience of living with ulcerative colitis (Dudley-Brown, 1996). The purpose of this study was to gain information about the experience of living with UC from the perspective of two males and one female. The themes that emerged were: uncertainty surrounding the length of time between exacerbations of symptoms, fear and humiliation accompanying stool incontinence, the desperate need to find successful treatment and return to a normal life, the profound effect on family life, social life and work life, and the feeling of being controlled by the disease. The study themes supported the literature that described the individual's uncertainty and humiliation accompanying stool incontinence but contrasted with research literature indicating that patients with IBD typically maintain good social functioning.

A grounded theory study by Brydolf and Segesten (1996) described the experiences of 28 young adults and adolescents living with UC, 10 of whom had an ileostomy. The aim of the study was to gain a deeper understanding of the adolescents' experiences of how it felt to live with UC. Participants described two sequential components of living in a state of transition followed by a subsequent altered lifestyle. The central concept of this study was living space, which was described as "the sphere one acts within in one's daily life, including routines, physical, social and cultural activities and traditions one has acquired" (Brydolf & Segesten, p. 45). Living space

changed depending on age, developmental stage, and health. Individuals, in this study, described feeling differently from their former selves and from their peers due to living in a state of transition from child to adult at the same time as needing to deal with symptoms of CD. This led to feelings of alienation and fear. Fear, loss of energy and alienation led to reducing living space in order to cope. Reducing living space was a strategy used to manage the new situation. For example, all participants experienced a dependency to being near a toilet, which limited their ability to go far from home or familiar surroundings. Feelings of support, confidence in self and role identification as an adult, expanded living space while perceptions of lack of support, disbelief in self and role identification as a child or patient reduced living space. Support, according to participants, often came from family, friends, teachers, and health care professionals. Lack of support was described as overprotection and decisions made without consulting the adolescent. Confidence in self meant to trust one's own capabilities while disbelief in self meant feelings of insecurity and inability to do things right. Role-identification as a child or patient encouraged dependency while role-identification as an adult promoted independence. The results of the study indicated that the most important factor is an environment where the adolescent is regarded as an independent person with the ability to make decisions. It emphasized the need for involving family members in the care of patients with UC but also stressed the importance of allowing the individual with UC to make decisions regarding treatment and care.

In-depth studies, such as the ones described, are required to describe the impact of living with CD from the patient's perspective. Living with CD results in the need for significant changes in lifestyle and takes a toll on physical well-being at the most productive time of the individual's life. CD has a significant effect on the psychosocial health of the individual and family members. The social toll of CD also affects the future health care of clients, who are ill at an earlier age and for a longer period of time. The fatigue, body image disturbance and limitations imposed by

moderate or severe flare-ups impact on all aspects of daily living.

The lack of research from an individual's perspective in living with CD supports a statement by Lindsey (1997) that health care professionals tend to focus on the physical aspects of a disease such as measurement of symptoms and treatment while clients focus on the subjective experience of their disease. Hernandez (1991) found that clients with diabetes often perceive advice from health care providers as unfeasible or inaccurate given their subjective experience that is, health care providers have inadequate understanding of what it is like to live with a chronic illness such as diabetes and therefore are unable to provide relevant advice or care. The current study was designed to overcome some of the gaps in the literature by explaining the personal experience of women living with CD every day derived through in-depth interviews. The grounded theory methodology used in this study is described in detail in chapter three.

CHAPTER THREE

Methodology

Overview of Grounded Theory

This grounded theory (Glaser & Strauss, 1967) study using the emergent fit mode (Glaser, 1978) was an investigation of the experience of women living with CD. Grounded theory refers to the collection of data grounded in fact and generating theory from that data (Stern, 1980). This method of inductive theory development allows the generation of a theory that accounts for behaviour that is relevant and problematic for those involved (Glaser). The emergent fit mode of grounded theory is used when there is a theory already developed that might be useful. The researcher recognized many similarities between diabetes and CD and posited that Hernandez' (1991, 1995, 1996; Hernandez et al., 1999; Hernandez et al., 1997) theory of integration might be relevant to women's experience of living with of CD. Using the emergent fit mode, the researcher begins with the theory but "starts correcting his early thoughts and follows the grounding in his subsequent theoretical sampling" (Glaser, p. 108). The purpose of using an existing theory is to verify or expand it through the collection of data (Glaser). Therefore, grounded theory using the emergent fit mode was chosen as the methodology most suited for this study.

In this study, the goal was to generate a theory that explained the experience of women with CD from their perspective. The theory of integration (Hernandez, 1991, 1995, 1996; Hernandez et al., 1999, Hernandez et al., 1997) was used as a starting point for the subsequent analysis but was modified as required by the data collection and analysis. The emergent fit mode provided an ideal technique for exploring the usefulness of the theory of integration. Grounded theory enabled the researcher to discover a new perspective of the experience of CD despite her previous knowledge and preassumptions about CD (Stern, 1980).

Theoretical Sensitivity

According to Glaser (1978), grounded theory looks for what is, not what might be. Concepts come from the data, are grounded in the data and must not be forced through researcher preconceptions. The researcher must trust that emergence of a theory will occur. While constantly comparing, coding, and analysing, it was necessary to ask two formal questions, which were: "What is the chief concern or problem of these women living with CD and what accounts for most of the variation in processing the problem? And secondly what category or property of category does this incident indicate?" (Glaser, p. 4).

A researcher's preconceived assumptions can be a major detriment to theoretical sensitivity therefore it was necessary to identify these preassumptions up front. Once preassumptions were recognized, effort was expended throughout the research process and with the guidance of the research advisor to "hold these at bay" so that they did not inhibit the analysis and discovery process. This proved to be one of the most difficult aspects of the research and will be described in more detail in the next section.

Researcher's Assumptions Related to Crohn's Disease

In grounded theory, the researcher is the instrument that uncovers the perspective of the participant through open-ended questioning and constant comparative analysis. This was a difficult task given the researcher's many years as a health professional. It was necessary to make a conscious effort to eliminate preconceived beliefs and assumptions about women living day-to-day with Crohn's disease. The purpose of acknowledging one's preconceptions is so that the research process can begin with a researcher who is theoretically sensitive and who could remain totally open to what the participants convey. Attention to theoretical sensitivity continued throughout the research process. The ability to hold preconceptions at bay is very difficult for beginning researchers and requires the guidance of someone who is well-versed in grounded

theory methodology. In this case, the researcher has had clinical experience with many patients with CD and has been involved with the Crohn's and Colitis Foundation of Canada for about six years. As a result of personal and professional experiences with individuals with CD, the researcher had developed a number of beliefs and assumptions about living with CD that were deeply ingrained and unrecognised as deterrents to uncovering the participant's experience of CD.

The first task in dealing with one's preassumptions is to acknowledge them prior to beginning data collection. Recognizing and listing pre-assumptions forces the researcher to consider what type of information needs to be bracketed or put aside. The following are personal and professional assumptions that were identified at the beginning of this study:

One assumption was that women experience more bothersome symptoms than men with CD and these symptoms do not always respond to treatment. Symptoms experienced by women may be related to hormonal or biological differences or it could be that women are more likely to seek treatment earlier than men when symptoms occur. It appeared that there is bias on the part of the medical profession in treating men versus women with CD, which is why the researcher decided to limit this study to women.

The next assumption was that adherence to medical therapy is necessary to help control symptoms of CD. It was also assumed that knowledge about CD enhances adherence and management of symptoms. It seems that women's symptoms of CD are severe and intrusive on their day-to-day living. It also appeared, in the researcher's experience, that women with CD experience great frustration in dealing with health care professionals. An assumption related to the researcher's experience is that positive relationships with health care providers may influence adherence to therapy and may help to decrease the feelings of depression related to unrelenting symptoms. It was also assumed that living with CD involves adaptation and coping processes, and, therefore, social support is an important factor in the management of CD on a day-to-day

basis.

The researcher was unprepared for the impact that her preconceptions had on the data collection and analysis process. Mere acknowledgement of one's preconceptions is insufficient. Holding assumptions "at bay" proved difficult, even impossible at the beginning, and was a continuous struggle throughout the research process. The researcher frequently lapsed into the health care professional role and as a result was unable to remove blinders without the guidance of the research advisor. This resulted in directive instead of open-ended questioning, leading questions in response to comments made by participants, failure to identify questions that would uncover participants' experience and difficulty in seeing what participants were saying both during the interviews and in subsequent analysis. The researcher had many moments of frustration, which stalled the analysis process at times. On at least two occasions, the researcher tried to finish the theory prematurely and thus the writing was contrived or forced. The ongoing struggle with preconceptions resulted in the requirement for one additional interview with study participants. Glaser (1978) states "sticking to the study and finishing it is a difficulty of self control found by many grounded theorists who wish to move on before they are finished" (p.6).

Grounded Theory Methodology

Constant Comparative Method

In grounded theory, data collection and analysis occur simultaneously. The most important feature of grounded theory is using the constant comparative method of analysis. The constant comparative method consists of the continuous coding and analysis of data in order to generate a theory. The overall process of constant comparing involves "continually checking out concepts and producing properties of categories and theoretical codes to relate to them" (Glaser, 1992, p.76). According to Glaser "the constant comparative method of coding and analysis simply produces a core category and its related property, and lesser important categories (p.77).

Coding

Constant comparative analysis involves coding data into two types of codes, *substantive codes*, and *theoretical codes*. Substantive coding begins with open coding and ends with selective coding. Open coding involves line by line coding in which each incident or piece of data is compared to every other incident; this is how the initial concepts (categories) are derived. Once concepts have emerged, then incident is compared to concept to generate the properties of these categories (Glaser, 1992). Open coding ends with the discovery of the core category or core variable.

During selective coding, the researcher delimits coding to only those variables that related to the core variable (Glaser, 1992). Delimiting allows the researcher to spend time and effort on data that are relevant because "the core variable becomes the guide to further data collection and theoretical sampling" (Glaser, 1978, p.61). The constant comparative method of incident to concept continues but now coding is limited to only the concepts that related to the core category. Saturation of the core category occurs through selective coding.

Theoretical codes are "the conceptual models of relationship that are discovered to relate the substantive codes to each other theoretically (Glaser, 1992, p. 27). During theoretical coding, the researcher theoretically codes the relationship of the core category to its properties and other categories.

Theoretical Sampling

Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes and analyzes his data and decides what data to collect next and where to find them in order to develop his theory as it emerges (Glaser, 1978). In theoretical sampling, data collection is controlled by the emerging theory, that is, participants are chosen according to the indications of the emerging theory. The number or type of participants is not

predetermined but is dependent upon the emerging theory. Once the core category is saturated, no more participants are needed and the data collection ends.

Memoing

Memos are the “theorizing write-up of ideas as they emerge while coding for categories, their properties and their theoretical codes. They are written up as they strike the analyst while constantly comparing, coding and analysing” (Glaser, 1992, p. 108). Memoing was an integral part of analysis and was an ongoing process throughout constant comparison, coding and analysing. According to Hernandez (1996), memoing is useful to reduce the number of categories, provide leads as to where to go next with interviews or theoretical sampling and to check hunches or discrepancies as the theory is emerging. A memo can be a few paragraphs or several pages. Whenever an idea or conflict arises in the researcher's thinking, coding is stopped in order to record ideas as memos. Memos help in the organization and write-up of the theory. After the analysis has been completed, memos are sorted and ordered to allow the write-up of the theory.

Pilot Interview

Prior to beginning the interviews, a practice interview was conducted to structure and test the questions to be used for the actual research. Also, during the interviewing, the researcher used open-ended questions that were carefully worded to avoid leading the participant and to let the participant tell her story (See Appendix A).

Study Participants

Three of the participants for this study were recruited locally through a gastroenterologist's office and/or members of the Crohn's and Colitis Foundation and the fourth was recruited via the research advisor. The criteria for participants included English-speaking women from the ages of 23 to 55 who had been diagnosed with CD for more than five years. It was presumed that women would need at least five years living with CD in order to have had time

to go through any stages that might be associated with living with CD. Participants were unknown to the researcher. Each participant chose a code name to be referred to throughout data collection.

The first participant, Kate, was suggested by a member of the local Crohn's and Colitis Foundation. During her interview, she wondered if the experience with CD would be different for someone who had been diagnosed for longer than six years and for someone who had children.

As a result of Kate's comment, the researcher looked for a woman who had CD for over ten years and who had a child. The next participant, Thirteen had been diagnosed for eighteen years and had a daughter. Thirteen wondered during the interview if the experience of CD may be different for someone who was experiencing more acute symptoms as she had been in remission for several years and did not feel that CD had interfered much with her life.

The third participant, Pokemon, was chosen because she was in an acute flare-up of CD. Pokemon had just recently been discharged from hospital after a severe flare-up requiring surgery and subsequent postoperative recovery in ICU. Pokemon wondered what life would be like if she eventually had to have surgery, which resulted in an ileostomy.

The fourth participant, Mary Ann was living with the effects of CD each day for the past 12 years. Her onset of CD was sudden and resulted in emergency surgery for a perforated bowel.

Protection of Participant's Rights

Ethical clearance for this study was obtained through the Research Committee of the University of Windsor Faculty of Nursing. Initial meetings with each participant began with obtaining formal written consent (See Appendix B). At this time, the study was explained and questions about the study were answered. The consents outlined the purpose of the study, assured the participant of confidentiality by use of a code name and the secure storage of the interview tapes and transcripts. It also stated the participant's right to leave the study at any time. Each participant was offered a copy of the study report upon conclusion.

All transcripts, audiotapes and memos relating to the study were kept in a locked drawer in the researcher's home office. All information was identified by code name only. Transcripts were typed verbatim from audiotapes by a hired typist. All participants gave permission to use the findings for educational purposes and publication.

Conduct of the Study

At each of the first interviews, the participants were interviewed using open-ended questioning (see Appendix A). The interviews began with the open-ended question "Tell me what it is like to live with CD now that you have had it for six (or more) years. General questions throughout the interviews were used to focus the participant on the experience of living with CD such as " What were you feeling like before you were diagnosed? Tell me more about your experience in the hospital?"

The interviews were audiotaped and transcribed verbatim. Each participant was seen twice for formal interviews at eight to ten month intervals at a location of their choice. Interviews lasted from one to two hours each. The second interview clarified statements or issues from the first interview, for example, "You said there were aspects about CD that were good. I wondered if you could tell me what that means?"

The second interview also explored relationships with health care providers, for example, "Describe the perfect health care provider and how could they be most helpful to you?" Another open-ended question was, "Is there anything else you can tell me that would help someone like me, who doesn't have CD understand exactly what having CD is like?" Participants were also contacted by email for clarification of data during the analysis process and finally, Kate and Thirteen were interviewed a third time to elicit more information as the categories for the turning point phase were not saturated, due to problems described earlier related to the researcher's preconceptions.

This study discovered the experience of living with Crohn's disease from a woman's point of view. It also explored how the theory of integration fits with the experience of women living with Crohn's disease. This was accomplished by interviewing four women individually on at least three separate occasions and following up with email questions during the analysis resulting in prolonged exposure to the participants. The findings of this study indicated that living with CD does involve a process of integration whereby individuals with CD move through similar stages described by Hernandez (1991) in the theory of integration.

CHAPTER FOUR

Findings

Overview of Findings

The results of this study verified the existence of a three-phase process of integration in living with CD. Findings indicated that Hernandez' theory of integration (1991, 1995, 1996; Hernandez et al., 1999; Hernandez et al., 1997) was a useful theory for explaining the experience of women living with CD. The theory of integration was first generated by Hernandez (1991) through grounded theory research of clients living with Type 1 diabetes. In Hernandez' theory, the experience of living with diabetes consisted of a three phase process of integration which included having diabetes, turning point and science of one. This three-phase process involved the integration of the personal self that existed prior to the diagnosis of diabetes and the diabetic self, which emerged after diagnosis. The phases of integration identified in this study had similarities and differences from the experiences of integration described by Caucasians with Type 1 diabetes and in First Nations clients with Type 2 diabetes (Hernandez, 1991, 1995, 1996; Hernandez et al., 1999). This chapter will describe a similar process of integration of the personal self and CD self that emerged through interviews with four women with CD. The personal self refers to the person that existed prior to the diagnosis of CD, while the CD self refers to the new entity that emerged upon diagnosis. Integration of the personal self and CD self increases as the individual moves through the phases of integration. The phases found in this study were: having CD, the turning point phase and science of one. Lifeways, described by Hernandez (1991) "as characteristic patterns of thought or action used without conscious knowledge" (p 99), were found in the first and third phases that kept the individual in that particular phase. Kate, Thirteen and Pokemon were found to be in the "having CD" phase while Mary Ann was in the last phase of science of one. However, it is important to note that being in phase three is not necessarily better than being in phase one; as individuals move through the phases, integration increases.

Phase One: Having CD

"Having CD" began with the diagnosis of CD. The focus in the having CD phase was on being and feeling normal, that is on living life as close to the way as it was prior to having CD. Lifeways emerged that kept the participants in the having CD phase by allowing them to feel as normal as possible. These lifeways enabled participants to maintain their usual ways of living through denying the existence of the CD (denying), emphasizing aspects of life that are the same as prior to CD (normalizing), downplaying the impact of CD (minimizing) and speaking about CD as an entity separate from themselves (personifying). The result of the use of these lifeways was that integration of the personal and CD selves was minimal in this initial phase. All of the participants exhibited the denying, normalizing and minimizing lifeways. Two of the participants used the personifying lifeway.

Denying

Participants were able to feel as if they were leading a normal life by denying the existence of CD. By denying CD, participants were not acknowledging CD because if they did, "Then I'm sort of admitting that it's affecting me, it's becoming an obstacle in my life." as quoted by Kate. Denying was demonstrated by 1) not accepting the diagnosis of CD and/or ignoring CD; 2) believing that CD was a temporary condition that could go away; 3) refusing to follow or disagreeing with medical advice; and 4) not being interested in finding out more about CD."

Denying was illustrated by not accepting the diagnosis of CD or trying to ignore CD as indicated in the quotes below by Kate, Thirteen and Pokemon,

I think I have a sort of acceptance problem that I have CD. I go so many months feeling fine and not having a single symptom.

He wanted to put me on drugs and I left his office because I was kind of ticked at his diagnosis.

When I was first diagnosed, I would just lay on the couch all day. I would just get up to get my son something to eat and that and maybe play a game with him... all I wanted to do was lay down and sleep and not try or even think about what was going on.

Believing that CD was a temporary condition that could go away was also a common

form of denying as shown by Thirteen and Kate,

Actually I thought from that day on, I thought I would never have Crohn's, that I never had Crohn's. I thought once they took it out, I never had it, and about ten years after I had my bowel surgery, I went in to give blood and the girl told me I'm never allowed to give blood, that I'm a Crohn's patient and that I, even though it's not flared up, I have Crohn's in me...

The only thing is when I had my Crohn's the first time, well the first time the pain was on my right side and now I have it on my left side.

I am pretty active and I live my life, I think, as if I don't have Crohn's sometimes and it, I think once those symptoms kind of start, it's a big reminder because the last time I was in the hospital, my doctor made the comment to my family that he thought I was somewhat in denial that I had the condition just because, um I think because I had refused to at one time, I had refused an ongoing, like maintenance therapy drug because I was symptom free for so long...

Sometimes the belief that CD was a temporary condition was promoted by comments made by health care providers. One participant, Thirteen believed CD was gone after surgery because of her perceptions of what the physician said,

I thought that when they took the Crohn's out, he told me he went all through my bowel and that it was all isolated and that he cut past it and got it all...I told people that I didn't have Crohn's anymore and that's what I believed, that I didn't have Crohn's anymore. But I also knew I could possibly get it back in five or ten years... He gave me three scenarios when I had my surgery. He said I could go to the bathroom right after I ate...that I could get my Crohn's back or I could be fine. I told him I chose to be fine.

Another type of denying that was used extensively was not taking medication as prescribed or disagreeing with the treatment that was prescribed as evidenced in the following quotes by Kate and Thirteen,

There's a tendency to not want to be on the drugs because you feel okay and the longer you go feeling okay, the less you really accept the whole reality that there is even anything wrong with you, so why do you need to take pills... I can see his point, the doctor, that he would prefer that I stay on a maintenance therapy but personally when I was on the Pentasa, I felt it did very little for me.

I've tried taking Pentasa and it made me sick, so I've stopped taking it, and I go see him, actually tomorrow to tell him I haven't been taking it for the last three weeks or a month...

I've been sort of adverse to the idea of being on medication because I don't feel that I'm a chronically ill person... Day to day my life is so normal that to take four pills just to make sure I don't get a flare-up, it doesn't make sense to me...

Disinterest in learning about CD was another way of denying the existence of CD. There was no reason to learn about CD unless a participant acknowledged its existence as described as described by Thirteen, Kate and Mary Ann below,

The only time I want to read about Crohn's is when I'm not feeling well. When I'm ok, I don't like to think about it. The disease like any other can consume your life if you let it, so when you feel good, the last thing you want to do is read about it.

I think too, when you're not experiencing the symptoms and you're not really having that much problem with it, there's a tendency to get away from the information or, I haven't been seriously ill with it for five years now, so my knowledge is a little more limited.

In the beginning, I found it really difficult to deal with my illness, thus my recovery from surgery was long, plus my willingness to look after my ileostomy on my own was shaky at best. I hated to even look at my stoma or the pouch. I refused to read any materials I was given. I just didn't see it as any kind of positive thing at the time.

Participants would deny the reality of CD by either not accepting the diagnosis of CD or believing that CD could go away, by refusing to follow medical advice that is perceived as irrelevant or unhelpful, and by not being interested in learning about CD. By using the lifeway denying, participants did not acknowledge CD, therefore, and remained in the having CD phase.

Normalizing

A second common lifeway in the having CD phase was normalizing, where participants continued to live life as normal and emphasized aspects of their lives that are still the same as prior to CD. Participants showed evidence of normalizing by 1) pushing themselves to achieve what they used to achieve or what others their age can achieve; 2) insisting that CD did not interfere with their previous or usual daily routine; and 3) learning to do the things that would prevent CD from interrupting their usual ways of living.

Participants were able to feel normal by pushing themselves to do the type and amount of activities that they could do prior to CD diagnosis or to engage in activities that they believed others of their age would or could do. The following quotes by Thirteen, Pokemon and Kate illustrate this,

I know I was tired but I still did stuff...I still got meals and everything, so I must not have been doing too bad.

Sometimes, I feel like I'm pushing myself to do stuff around the house but lately there's been a lot of stuff to get done so...We just finished doing the siding on the house-washing it and the windows and that kind of stuff. I do a little too much work...

I often lapse into denial of having CD and push myself as hard as I can to know that I can live like any other 27 year old...I guess I just mean by that when I have times of feeling good and I'm doing everything that everyone else is doing and I think I'm fairly busy. I work full time and I'm still working on my degree, um taking courses and I'm active in some things like, I belong to curling leagues...and other things that are always going on. Sometimes I get to a point where I start having symptoms and I just get angry because I think that's getting in the way of me living a normal life and sometimes I think, "Well you have Crohn's disease" and it just doesn't seem like a reality all the time because there's such long periods of time where I am symptom free...I get into these periods of time when I'm feeling good and doing all these regular things and then sometimes I feel myself starting to wear down and I'm tired and I'm starting to have the bowel symptoms and I'm thinking "What's going on?" and it's just a big reality check. And then I realize, "Well you know, you have this condition. It didn't just go away." But it's not always there and I just want to be that way because there's no one else I know my age...there's no one else in my life that is my age that is really dealing with that so I mean I get to thinking I would just like to be like everybody else, that I just want it to be that way...

Participants insisted that CD did not interfere with their every day routine thereby normalizing their current day-to-day experiences as stated by Thirteen, Pokemon and Kate,

When I got hired, I never told them I had Crohn's because I figured it wasn't going to interfere with my job

I only need the one day but it's because the Graval, Demerol is going through your system. I just, once I sleep all that off and then I just go back to work, as normal, and I just watch what I eat for a little while and then I'm feeling normal within a couple of days, so it's not really that debilitating, like these types of flare-ups...

I guess, sometimes I guess, like an average person, sometimes I skip breakfast or I have a granola bar when I get to work. I don't really-it doesn't really affect my workday at all. I eat like normal.

Individuals went to great lengths to work around CD by taking actions aimed at avoiding discomfort or at getting back to a normal routine. The statements below by Kate and Thirteen show that they learned to do things that would prevent CD from interrupting their usual ways of living.

I think because you're always conscious of it, that you have to work around it and you just every day is a different day and you just have to, every flare-up is a different flare-up and you just I mean you're constantly working to make your life or it fit into your life.

I really think I talked myself out of it a couple of nights. I would actually come down here and I would sit on the couch, sitting up and I would just have little sips of water and if I could sort of fight the nausea and even get some sleep, if I was sitting up, then I would get up in the morning and it would be like I got through another night without an attack.

I believe that you have to develop an inner strength to not let the disease totally control you and to push how you may not be feeling the greatest to the back of your mind and put your thoughts towards enjoying what you had wanted to do that day.

With normalizing, individuals were at least showing some degree of acknowledgement or accommodation of the CD. However the focus was on the ability to be and act the same as one was prior to CD diagnosis. Normalizing was another lifeway that kept participants in the having CD phase.

Minimizing

Minimizing was a third lifeway in the having CD phase. Participants were able to feel as if they were leading normal lives through minimizing. Minimizing allowed them to downplay the impact of the CD on their lives by 1) demonstrating that CD did not affect them as much as others who have CD; 2) insisting that the CD was a minor inconvenience or discomfort that did affect them but not all of the time; 3) attributing any new body cues or lifestyle changes to other aspects impacting their lives and not the CD; and 4) forgetting about CD or pushing it to a small corner of their lives.

The following quotes by Kate, Pokemon and Thirteen demonstrate how CD did not have as much of an impact on them as it had on others they have met.

I know a lot of people with CD. I have never had to have surgery. I know that there are also people that have it that are much more seriously ill than me so I tend to feel lucky because I have had a pretty normal life and yet I have a flare-up here and there and it sets me back but it's not by any means debilitating or anything that gets in the way of a normal life... I think I'm fortunate in a way when I do compare myself to other Crohn's patients that have had some very extreme types of surgery and have a colostomy or that type of thing. I think I'm fortunate because I can eat pretty much anything but compared to those cases I'm one of the fortunate people the way that my disease has progressed and the way that I live.

They say that most people if they get Crohn's back, it's usually in the first five years if not ten and I went twelve years so I consider myself very lucky...I guess I feel I've been

pretty lucky, though with my CD. Even when I was first diagnosed with it, oh I was bad for about a year. After about a year it settled down. I never have anything most of the time.

It was really scary when I was first diagnosed with this disease because I didn't understand it and I wasn't sure how far it would take me. Now I don't really feel I have it as bad as some other people get it and I'd say it's just really scary when you first discover this thing. There are things that are worse you know It scares me sometime to think about death, colostomy bag and that and that kind of scares me. I don't want to think about that but if it comes it comes. I'm still alive so...

Kate, Pokemon and Thirteen listed many instances of minimizing where they described how CD was only a minor or temporary inconvenience or discomfort and as something with which they could live.

On average I can maybe expect maybe two or three times a year for it to knock me off my feet, but at the same time I could possibly look forward to two years without any signs of it. A little bit of symptom to remind me it's there and that sort of thing but I honestly think that I could get through, I mean maybe even the rest of my life.

Maybe it's back, but not as severe as what he is telling me. But if it stays like this, then that'll be fine because I'm not really inconvenienced by it, not anywhere near what I experienced 20 years ago.

Yeah like I would only have small cramps once in awhile and that would last two or three days and there was nothing to incapacitate me or anything like that, just little things, and then I still had the diarrhea, but he had me on the codeine so that controlled that pretty much too and I went anywhere I wanted to.

It just seems-it controls what I do but not all the time just those times where I'm having problems with it. It controls my workday if it's happening when I'm at work. It controls my sick time because I'm off for periods of time, um and then I find it's difficult when I'm having an attack and I've come out of the hospital or anything like that. I have such a big dependency on people and I hate that part of it...

I always tell people that I live very well with it and I guess by that I mean that it-like I've said it controls my life when it's there but I mean I think have a really good quality of life so it always depends on the degree or extent that you have it...It's very livable, like it's not um it can be debilitating and there's really bad days but there's lots and lots of good days...

At times participants minimized by attributing new body cues to other aspects of life instead of CD. Examples of attributing body cues or lifestyle changes to other conditions by Kate, Pokemon and Thirteen are as follows,

My CD has been bothering me, and it seems too like, the fibromyalgia, with it is the chronic fatigue so it's been kind of an upward battle just battling the fatigue and trying to maintain a normal lifestyle...

I've been sort of adverse to the idea of being on medication because I don't feel that I am a chronically ill person. I'm probably more tired than the average person but I also have the iron deficiency

They said my iron was really low and they said there was some blood in my stool but I never noticed anything so I don't know how it got so low. He thought it was from my bowels something was wrong but I didn't think so. I don't know I had always had really heavy periods so that's what I thought it was but he didn't—he thought it was something else

As far as I'm concerned, I still run my life like I did before. I don't, it doesn't hinder what I do, except for my tiredness, which could be my sugar, so I don't want to blame the Crohn's for that.

I am hoping my bowel discomfort and tiredness can be relieved by a higher nutritional approach and staying away from certain foods... But it's helping. I feel much better and more alert but then again that might be because of sugar, balancing sugar more than the Crohn's...I eat for sure five times a day and usually around the same time but that's because of my sugar...If I don't, I get really lightheaded um get headaches and I've gotten shaky at times-but then I find at the end of the day I'm really tired. So as long as I keep it balanced, my energy level is fairly decent...I think it's easier on my Crohn's because I'm not consuming as much food. Like having three larger meals. I have five or six small meals so I think it's easier on my bowel and I also think it's easier because I don't eat sugars and I don't eat white flour. And when I do eat those, the bowel is sore. So I actually think they complement each other be not being able to eat those things...Then I probably suffer more with my sugar than I do with my Crohn's

Forgetting about CD or pushing CD to a small corner of their life meant that the focus of living was still on the personal self. When asked to explain "a little discomfort in my bowel" that she had mentioned by email a few days earlier, one participant was unable to recall that she had this discomfort. Quotes made by other participants confirmed this thinking,

You see my symptoms are good now, so I hardly think about it right now, other than having to go to the washroom, you know that's the only thing wrong. I hardly think about having a disease.

No um, I seem to go in these episodes where I'm like that for a month and then I go a whole month and nothing happens and I forget what that's like-to go through it and no sooner I'm thinking I'm doing good for this period of time and it kicks in again and then back to life revolves around the bathroom again. Right now I've been good for at least a month not having to be concerned with that at all...

Minimizing was strategy that was used frequently by all participants and indicated that

participants were acknowledging CD more readily than when they were denying CD. They admitted that CD was affecting them at times but downplayed the overall impact that CD was having on their lives. Participants also looked for other reasons for feeling the way they did in order not to attribute symptoms to their CD. When CD was not active, participants talked about forgetting about CD as if it only occupied a very small corner of their life. The aim in minimizing was still to live as normal.

Personifying

Two participants in this study used personifying of CD by speaking about CD as if it were a separate entity that operated and reacted on its own and over which they had minimal control. This personifying allowed them to keep CD at arm's length thus protecting the integrity of the personal self by labelling CD as "it" or "that" and the personal self as "me" or "I". The following quotes from Kate and Thirteen illustrate personifying,

I thought once they took it out, I never had it. But I also knew I could get it back in five to ten years. I never thought that it was smoldering away in there...

You can monitor it by trying to eat things you know won't bother you and taking drugs to try and control it, but there's really no-I just think it has a mind of its own. It does whatever it wants to, so even when you think you're controlled, I don't think you really are.

I don't know if there is a formula for keeping it consistent. I think it's just got a mind of its own and at the moment, it doesn't like the carrot you ate or the whatever.

There's really nothing to do to prevent that because that's my biggest thing, like what can I do to prevent this when I'm just doing what I do every day and I'm not changing anything and it's still happening to me out of the blue. You know I just don't know how to deal with that...

Participants using this lifeway did acknowledge CD but as a different and separate entity from themselves. The main purpose of personifying was to hold onto the condition of still being the same or normal self.

All participants in the having CD phase used denying, normalizing and minimizing at various times during the interviews. However Kate would sometimes use these lifeways in combination with each other as demonstrated in the quotes below. The combinations used were

normalizing and minimizing, minimizing and denying and minimizing, denying, normalizing and personifying.

I just...Once I sleep all that off and then I just go back to work, as normal and I just watch what I eat for a little while and then I'm feeling pretty normal within a couple of days so it's not really that debilitating, like these types of flare-ups but it's sort of watching the extent of them.

I can foresee no further progression of my disease. I like to be confident in that I've pretty much stabilized for five years. I've learned how to cope with the attacks. I've learned to get smart to when an attack might be creeping up on me...I think I will get smarter at dealing with it and then maybe I can put it, put it off and almost out of my life.

I know there's times where I had such a good stretch and when I have had a good stretch like that I'm usually really positive um and I would say that you know it's really not that much of an inconvenience. It's there but it's not been there for me so I've been doing well and it hasn't affected me for so long that I do kind of forget what it's like. And I do think that I'm lucky in terms of the people that have Crohn's. Then when I'm in the hospital and they're talking surgery and they're putting me through these tests. I go through a real down slope where I just think you know this is the pits! This is such an inconvenience...

The three participants in the having CD phase had been in this phase from 6 to 18 years.

By using denying, normalizing, minimizing and personifying, participants were able to keep life as close to normal as possible and did not need to focus on the CD

Phase Two: Turning Point

In this study, it was not possible to explore the turning point phase in any depth because none of the participants in this study was found to be in the turning point phase. However, one of the participants, Mary Ann, had progressed through the turning point and was in the final phase, the science of one. It has been many years since Mary Ann was in the turning point phase and her recollection does not lend itself to a thorough description of this phase, but entry into the turning point phase happened when events in life brought a recognition that CD could no longer be denied, normalized or minimized.

I think that as I began to feel better physically and my Crohn's was under control and I recovered from my surgeries, I began to feel better mentally. Also I had to look for work and finish off a project that I had begun prior to becoming ill. Once back at work, I had to become more independent and learn about my illness in the workplace--Notice, I didn't say that I wanted the workplace to make accommodations for me. I also had to face the fact that, in a lot of cases, my illness would be a barrier to me taking certain types of jobs

and I had to change my life goals. I had planned to do another overseas posting, but that was no longer a possibility since excellent physical and mental health is a requirement.

It is very hard when you have been a healthy, independent individual, which I was, to suddenly be confined to a hospital bed, then confined to being an invalid for a period of time while recovery takes place and finally to know that you have to be aware of this illness and its results for the rest of your life. It means that one's reality has to change and that period of adjustment can be difficult especially if you are very ill in the beginning and in a weakened condition. It is also difficult to have other people react to you as a "sick person" and to have to depend on your family members to care for you both physically and in my case financially for a while because I had no job and no insurance. I believe there is nothing worse. It has given me an entirely different perspective on aging and illness, of going from this vibrant, independent person to this dependent sick one. It gets easier as your body recovers, but your reality is still different because this illness is always with you.

These statements acknowledge that CD is a permanent part of one's life. They demonstrate how CD had become the focus in life. Personal goals have to be adjusted to accommodate the demands of CD. Demands are also accommodated through learning about CD. It is not known how long Mary Ann remained in the turning point phase before entering the third phase, the science of one.

Phase Three: The Science of One

The last phase is the "science of one" where the individual gradually progressed out of the turning point phase and the focus is on living but, living as an integrated self (integration of personal and CD self). The focus is on living but living life with CD as indicated by Mary Ann, in the following series of quotes,

I find that I am more at ease with myself now than when I was first diagnosed and first had surgery. Sometimes if I let myself think about it, I can feel that I am living with a time bomb, that I can have a recurrence and a serious one at that, at any time. I have learned to live with my ileostomy and be grateful that it saved my life. I live as full a life as I can, realizing that there are some restrictions.

I often hear my sisters say to people who mention my health to them, how good I look now that I am back to my old self. They are wrong though, because I will never be back to my old self. That self changed in 1988. Yet our lives change for all types of different reasons. Mine changed because of a disease and a body altering surgery. I am grateful that I am alive and grateful that I can share some of my experiences to others who feel as I did.

I don't believe in telling people that their lives will be better with an ileostomy even though they may be very sick now. I do tell them that they will feel better, as I do-I can't

say that I feel sick because I don't, especially if they have suffered a long time with Crohn's or colitis. What I tell them is that their lives will be different.

My ileostomy is a constant reminder of the fact that I do have this disease, and this ileostomy affects my life significantly. It affects my work, my social life and my relationship with my partner.

Two lifeways enabled the ongoing integration of the personal and CD selves, in this study. These two lifeways, tuning in and engaging others, have allowed Mary Ann to live comfortably with her CD.

Tuning in

By tuning in to body cues caused by the CD, Mary Ann is able to make adjustments that allow her to engage in the activities she wants to do. The quotes below illustrate how the knowledge of her body, and the way it reacts to the CD, can be used to her advantage so that she can continue to work and socialize in a way that is acceptable to her.

After I eat, and what type of food I eat doesn't seem to make a difference, I need extra time to digest my food and use the washroom-plus I take a while in the bathroom. If I am meeting with clients in my own office I do not schedule any appointments in the half hour after the same breaks. I also need to eat regularly. If I get hungry, I get extremely uncomfortable so I cannot skip a meal or snack, nor is it any good for me to eat on the run. I will need to use the washroom and if I don't, I will be extremely uncomfortable and my discomfort will be all I will be able to focus on. Therefore I hate breakfast and lunch meetings though I attend them. However I'm usually in discomfort by the time they are over. Also I am sure everyone has heard jokes about the noises an ileostomy can make. I find that if I don't eat or only eat when I am very hungry, my ileostomy will make gaseous noises and they are extremely embarrassing let me tell you! It doesn't happen too often, but I am always aware of what might happen.

If I am going out to supper at seven thirty, for example, I will have a snack first-usually toast and tea. I cannot wait until seven thirty to eat or I will be uncomfortable before I eat that night. I go to the washroom again after supper, and then two or three more times before I go to bed...

The weekend is pretty much the same...On Sunday night in the winter I curl. That can be difficult at times. It means we have to eat supper by five p.m. because I will need to use the washroom before I leave for the rink, then get to the rink a bit earlier than most people so that I can use the washroom again before I go on the ice...

The ileostomy will also impact on such things as going to a movie or to the theatre. If I get home from work and want to go to the early movie...or I have theatre tickets...then by the time I eat supper...and get to the movie or theatre, I need to use the washroom again. The movie is not too bad, if I really have to, I can get up and go to the washroom but then I end up missing a good portion of the film, and I hate walking over people. So

usually I just sit there anyway even if I do need to use the bathroom...Needless to say, I prefer to rent movies and watch them at home.

On New Year's Eve, there is a celebration down on the waterfront...Normally I would love to go to that kind of event, but I know I can't now...There is no way I could go without access to a bathroom for four hours-the porta potties are no good for me. So I won't go to the celebration...So it's a restriction on how I would like to live my life. I adapt, because I wouldn't stay home from the party because of it, but still it will hurt just a little when everyone else leaves.

The type of clothing I used to wear like wearing close-fitting jeans and skirts and sexy panties and so on, was no longer an option. Now I have to search everywhere for full panties that have some spandex in them to keep my pouch in place. These types of panties usually come in black or this ugly colour of beige. Also I find wearing skirts uncomfortable unless I can find some with low-rise waistbands. Most of the waistbands sit right on my pouch. Usually I can find low-rise slacks and jeans but they have to have pleats in the front and pockets to hide the pouch bulge. Mostly I wear a lot of tops that come down over my thighs-I very rarely tuck in a top or blouse and go. Bathing suits are a problem as well. I haven't been able to find one that I really feel comfortable in. So I don't swim very often either.

Mary Ann has been in the science of one phase for over six years and during that time her personal and CD selves have integrated more fully. About four years ago, Mary Ann allowed herself to pursue an intimate relationship. Prior to that she was afraid the CD, particularly her ileostomy, would get in the way of such intimacy.

Engaging Others

Engaging others is another lifeway used to facilitate the merging of the personal and CD selves. Engaging others involved supportive or collaborative alliances with others. Three quotes below demonstrate how Mary Ann engages others to promote living successfully with her CD in her intimate life, work life and as a person with an ostomy.

I did worry a lot about how I was going to tell him about my ileostomy, but I figured it might not come up anyway. Before I didn't even go out on dates, but now I decided that I deserved some sort of normal relationship, but I wasn't sure that would go past a couple of dates and that would be it. As it turned out, it went further than a couple of dates and eventually I had to tell him. Telling him was quite difficult because I liked him very much and knew that I would be very upset should he not be able to accept my Crohn's and my ileostomy. Much to my amazement (and maybe much to my good taste in choosing a compassionate, loving man) he was quite okay with all my various ailments. He even downloaded information about the disease and the ileostomy surgery from the Internet so that he could get more informed. We moved in together last summer and things are still going well. I have not found that my surgeries affected my ability to have

a normal sex life, which I was concerned about because of the removal of my rectum and the fact that I have had a couple of fistulas in the vaginal-anal area a few times.

I have been very fortunate that my immediate co-worker who has the same job as myself is very understanding of my needs with regard to my ileostomy. For instance, if we are conducting an all-day workshop, she knows that I will be unable to facilitate any of the sessions immediately following the mid-morning break or the lunch break.

The pharmaceutical firms, though, are different. I take issue with every Rep. I meet who demonstrates the new ostomy products and I have written to Convatec, one of the largest suppliers of Ostomy products, on a couple of occasions, asking them how they come up with their designs-I don't know who their test groups are. I suspect older men!!! There is no concession made to the size of a person. I am short and slim, and a lot of the pouches are way too long and bulky for me, even the petite sizes. The pouch clips are large, bulky and the ugliest things-especially the Hollister ones. I told Convatec that I didn't believe they thought of their customers as people who are out there in the real world, working, going to school, dating, socializing, doing many types of leisure activities.

Integration is an ongoing process where the individual develops expertise about her body and body responses by tuning in. This tuning in lifeway provided the information required to make the necessary decisions and adjustments to accommodate her work, social and lifestyle preferences. Another lifeway used by this participant was engaging others to assist her in living successfully with CD. The use of these lifeways facilitated the ongoing integration of the personal and CD selves.

Comparison of Study to Hernandez' Theory of Integration

The findings of this grounded theory study indicated that Hernandez' theory of integration (1991, 1995, 1996; Hernandez et al., 1997; Hernandez et al., 1999) was relevant and useful to explain the experience of the women in this study who were living with CD. Many similarities as well as differences were found to exist between individuals in this study living with CD and the individuals living with diabetes described in Hernandez' studies. Hernandez identified a three-phase process of integration: having diabetes, the turning point and the science of one. The same phases were found in this study and were called having CD, the turning point and the science of one. The four women who were interviewed were found to be at varying phases of the integration process but similar to Hernandez' findings, most participants were in the initial phase where the focus was on being normal or trying to live as one did prior to CD

diagnosis. Only one participant was in the science of one phase where the personal self that existed before diagnosis, and the CD self that emerged after diagnosis more fully merged to become a new self that was mentally and physically healthy. The findings of each phase are described further in the following section.

Phase One: Having CD

In phase one, participants in the having CD phase used the lifeways, denying, normalizing and minimizing much like the individuals in the having diabetes phase in Hernandez' (1991, 1995, 1996; Hernandez et al., 1997; Hernandez et al., 1999) studies. But unlike Hernandez' studies, a unique lifeway used by two of the participants in this study, was personifying CD as if it were a separate entity that existed on its own. Further research needs to be done to determine if personifying CD is a common theme for those living with CD or an isolated strategy used by two of the participants in this study.

Phase Two: Turning Point

In this study there was not a lot of information on this phase other than it does exist. At least one participant in this study showed evidence of reaching a point where she could no longer deny, normalize or minimize CD. Several factors led to the initiation of the turning point, whereas, in Hernandez' (1991, 1995, 1996; Hernandez et al., 1997; Hernandez et al., 1999) studies, sometimes a single but significant physiological or psychosocial event was enough to initiate the turning point. In Hernandez' studies, individuals in the turning point phase could revert to the having diabetes phase or go on to the science of one phase. Due to the fact that only one study participant had experienced the turning point phase, it is not known how long individuals could remain in this phase or if some individuals in the turning point phase revert to the having CD phase rather than proceeding to the science of one phase, similar to the experience of a female participant with Type 1 diabetes (Hernandez, 1996).

Phase Three: Science of One

In this phase, the lifeways used were tuning in and engaging others which are similar to Hernandez' (1991, 1995, 1996; Hernandez et al., 1999; Hernandez et al., 1997) lifeways but Hernandez identified many additional lifeways in this phase. As in Hernandez' science of one phase, the individual in this study used her own unique approach during integration of the CD and personal selves through use of this tuning in process. This tuning in process or body listening process in the science of one phase has been called self awareness work by Hernandez and consisted of the lifeways of body listening, body knowing, body balancing and engaging others (Hernandez et al., 1997). Although only one participant reached the last phase in this study, there is indication that this type of self-awareness work was occurring. The participant in this phase had an ileostomy as a result of her CD and the ileostomy was a constant daily reminder of CD, which may have been a catalyst to reaching the third phase and promoting the integration process.

There were many similarities and some differences between the current research findings of integration in women with CD and the theory of integration of those with Type 1 diabetes and Type 2 diabetes (Hernandez, 1991, 1995, 1996; Hernandez et al., 1997, Hernandez et al., 1999). It is not known if the differences are due to the differences in the way diabetes and CD are experienced, or whether these differences would disappear after theoretical sampling to the point of saturation of the theoretical categories. Hernandez' theory of integration was found to be a useful theory for explaining how women experienced life with CD and was readily modifiable to fit this experience.

CHAPTER FIVE

Discussion

Overview of Discussion

The emergent fit mode of grounded theory was the methodology used for this study starting with Hernandez' (1991, 1995, 1996; Hernandez et al., 1999; Hernandez et al., 1997) theory of integration. The findings of this study revealed that participants living with CD go through a similar process of integration as those individuals living with diabetes in studies conducted by Hernandez. The similarities and differences between the theory of integration in individuals with diabetes and the theory of integration of participants with CD from this study have already been delineated at the end of chapter four and will not be repeated here.

Included in this chapter is a comparison of the findings of this study to other research literature about individuals with IBD and other chronic illnesses. Also included are limitations of the study, followed by a section describing the rigor of this study using evaluative criteria specifically for grounded theory (Glaser, 1978, 1992) and qualitative inquiry in general (Lincoln & Guba, 1985). Finally the chapter ends with a section on suggestions for future research and the implications of this study for advanced nursing practice.

Comparison of Relevant Literature to Findings

In this section, the theory of integration will be situated within the current body of literature on chronic illness. There was one article that described themes and problems experienced by individuals with CD or ulcerative colitis. There were many articles related to individuals living with other chronic illnesses that had some commonalities to the integration process discovered in this study. The findings of these studies have been compared to the theory of integration to determine the fit between them and these comparisons are described in the next section.

A phenomenological study by Dudley-Brown (1995) described the experience of three individuals living with ulcerative colitis. The themes identified by Dudley-Brown were the 1)

uncertainty surrounding the length of time between exacerbations of symptoms; 2) the desperate need to return to a normal life; 3) the feeling of being controlled by the disease; 4) the fear and humiliation surrounding accompanying incontinence; and 5) the profound effect on family life, social life, and work. The desire to live a normal life was the focus of the having CD phase in this study and was a major issue for participants. The four other themes - uncertainty between flare-up of symptoms, the feeling of being controlled by CD, the fear of incontinence, and the profound effect on family life, social life and work could be aspects that might lead individuals to focus on the CD and move into the turning point phase.

Having CD

Denying

The literature was rich with research around the concept of denial. Denial has been described as a protective or adaptive cognitive process (Goldbeck, 1997; Goldberg, 1983; Kubler-Ross, 1969; Lazarus, 1983; Levine, Rudy & Kerns, 1994; Matthews, 1993; Wheeler & Lord, 1999) that allows the new diagnosis of a chronic illness to be slowly integrated or inhibited without producing excessive levels of emotion (Horowitz, 1983). This denial process is similar to when participants used the lifeway denying to reject CD. However denying was not merely a cognitive process as identified in previous research, but involved activities such as refusing to take medications for CD and not being interested in learning about CD.

Normalizing and Minimizing

Charmaz (1987) found that the individual living with chronic illness strives to lead a normal life by avoiding dependency and minimizing stigma. Koopman and Schweitzer (1999) found that participants with multiple sclerosis (MS), in their desire to maintain normalcy and as a response to finding meaning for their symptoms, would create possible reasons for why problems existed, would try to minimize the cause, would hide the disturbance and would find new ways to do things. The studies by Charmaz, and Koopman and Schweitzer describe participants concerns with leading or striving to lead normal lives. This is similar to the experience of women in the

having CD phase who sought to live as closely as possible to their prior lives by denying, normalizing, minimizing and personifying. The processes or themes described in these studies had similarities with the normalizing and minimizing lifeways. Some of the participants in Koopman's and Schweitzer's study reached a point where they "claimed their diagnosis" of MS and refocused their lives to include MS. This point could be analogous to the turning point phase of the integration process.

Science of One

Fleury (1991, 1996) reported that integrating change in chronic illness contributed to the development of new and positive health patterns and thus a new concept of self. Kralik, Brown and Koch (2001) found that for women, the struggle for a new identity between the old familiar self and the new self with chronic illness is a common occurrence and part of the process of coming to terms with the illness. The recognition that the major consideration in living with chronic illness is the development of a new self concept or identity is somewhat consistent with the participants' main concern in this study, that is the existence of the personal and CD selves. However, the current study went further by identifying the way this problem was resolved by participants through integration.

Michael (1996) discussed the need for change in living with chronic illness that meant giving up old habits and replacing them with routines that are consistent with the needs of the illness and finding meaning in illness. Michael found that the biggest challenge faced by the participants was the move away from the authority of the health care professional as the only source of expertise and to move towards their own wisdom and body knowing. The acknowledgement of expertise and reliance on body knowing is similar to the participant who was in the science of one phase. This individual was tuning in to body cues, responding to these body cues and engaging others to assist her to make necessary decisions and adjustments to accommodate her work, social and lifestyle preferences. The latter focus on the preference of the

individual was a major difference between the current study and Michael's work where the focus was on the needs of the illness.

Shaul (1997) described a transition process towards mastery in women living with rheumatoid arthritis (RA) that seemed to be comparable to the process of integration. During the stage of becoming aware and the stage of getting care, the women in Shaul's study reportedly experienced denial that alternated with fear of the unknown as women sought medical attention. These two stages can be compared to the having CD phase where individuals denied their CD and were not interested in learning more about CD. The third stage, learning to live with RA was characterized by disconnectedness as the women withdrew from activities, social relationships and work due to limitations imposed by the RA. This stage may be comparable to the turning point phase when the focus was on CD but there was not enough description of the turning point phase in the current study to establish this comparison. Transition towards mastery was a time of learning, living with unpredictability, and the establishment of new patterns that eventually led to a sense of connectedness and stability. Shaul states that this transition experience is influenced by individual interpretation of events which is similar to the process of integration where the individual develops a unique science of one known only to the self. The achievement of mastery included knowledge and awareness of the illness and how to manage it. This is in keeping with the findings of this study where the individual in the last phase developed expertise through tuning in to body cues and learned appropriate actions to take.

Tuning In

Price (1993) explored how healthy and chronically ill adults understand their body experience and described body listening as continuous, internal, varying in awareness from subconscious to full cognitive consciousness and critical to the process of choosing or attending to self management activities. Body listening is a learned response that occurs through increased awareness of patterns of changing body cues. A tuning in process or body listening process has been described as "an increasing awareness of one's body that occurs and facilitates the

integration of the personal and diabetic selves" (Hernandez et al., 1997, p. 22). One of the lifeways identified in the science of one phase in this study was tuning in. Tuning in involved knowing the body and the way it reacts to CD so that the individual is able to make adjustments that incorporate CD into the desired activities.

Engaging Others

The discussion of the importance of social support in coping with chronic illness is widely discussed in the literature. Kaplan, Cassel, and Gore (1977) described social support as the relative presence or absence of psychological support resources from significant others. Lindop and Cannon (2001) found that emotional and psychological support for women with breast cancer from their husbands or partners was identified as a significant factor in the ability to cope with illness and an important contribution to well being and survival. Similarly, Hough, Brumitt and Templin (1999) found being married played a protective role in chronic illness by reducing depression both directly and indirectly because of increased social support. Willoughby, Kee and Demi (2000) stated that high levels of social support and more adequate personal resources were associated with more effective coping and better psychosocial adjustment to diabetes. The lifeway of engaging others may be viewed as seeking support for living successfully with CD. However, the engaging others lifeway is different from the notion of social support in the literature because engaging others is initiated by the participant to achieve specific desired outcomes, as opposed to social support which is usually viewed as general or specific assistance provided by others.

A comparison of research findings to the substantive theory of integration has identified both similarities and differences. Similarities include a focus on being normal and the use of themes that have some commonalties with the denying, normalizing and minimizing lifeways; focus on illness resulting in a possible turning point; awareness of the old familiar self and the new self; moving away from the professional as the only source of expertise; and recognizing one's own wisdom and body knowledge gained through tuning in to body cues and responding

appropriately. Differences include the fact that denying in this study was found to be more than a cognitive process; integration of the personal self and CD self was not as suggested by other studies related to development of a new identity; and engaging others is an activity that is initiated and self-directed by participants as opposed to being provided by others. Although research studies had some similarities to the current study findings, none described the comprehensiveness of the process of integration that was discovered in this study.

Limitations of the Study

Limitations of this study could be categorized as researcher-driven limitations or research design limitations. Researcher-driven limitations were the result of inexperience with the complexity of the grounded theory methodology and the difficulty in dealing adequately with preconceptions. Theoretical sampling was not done and therefore categories and their properties were not entirely saturated in the turning point phase and science of one phase, leaving the grounded theory incomplete.

Research design limitations included the small sample size of four women. All participants were Caucasian and came from similar middle class backgrounds. The findings of this study indicated that the theory of integration was relevant to the women in this study but these findings may or may not be transferable to other women living with CD who have different backgrounds or to adolescents or children living with CD. Another limitation is that the study included only women so that the experience of men with CD might be quite different.

Additional research is required using theoretical sampling to saturate categories and their properties to further elucidate the turning point phase and the integration phase for those living with CD. Future research should include exploration of the experience of other women living with CD, women with ostomies, women with ulcerative colitis or women with other chronic illnesses such as multiple sclerosis or arthritis. Future research looking at the experience of men would also be beneficial to determine if there are differences in the experiences of men and women, which would result in the need for a unique approach to meet individual needs.

Evaluation of the Study

Grounded theory using the emerging fit mode (Glaser, 1978) was the method of inquiry for this study. Data were collected by interviewing four women on three or four occasions to identify how they resolved their common problem. This common problem was discovered to be the necessity of dealing with the two selves, the personal and CD selves. The resolution of this problem was the core process in this study or basic sociological process (BSP) of integration of the personal and CD selves. The grounded theory that emerged in this study was assessed using two sets of evaluative criteria: the criteria for evaluating grounded theory by Glaser (1978, 1992) and the trustworthiness criteria by Lincoln and Guba (1985).

Glaser's Criteria for a Good Grounded Theory

"A well-conducted grounded theory will meet its four most central criteria: fit, work, relevance and modifiability" (Glaser, 1992, p. 15). These four criteria attest to the plausibility of a grounded theory (Glaser, 1992).

"*Fit* means that the categories of the theory must fit the data that are collected, and that data are not forced or selected to fit the researcher's preconceptions or pre-existent categories from the literature, nor should data be discarded to keep an extant theory intact" (Glaser, 1978, p. 4). The three phase process of integration and many categories and their properties fit with the experience of the women living with CD. This is not entirely surprising given that one of the participants had advised Hernandez to study individuals who have CD because the theory of integration fit with her experience of living with CD. Glaser (1992) stated that the grounded theory would fit the realities under study if the data were carefully induced from the substantive area. The researcher's supervisor constantly challenged the overlay of the researcher's preconceptions and reviewed the coding of all data to ensure the fit between the data and the theory.

In order for a theory to *work*, it must explain the major variations or behaviours that occur (Glaser, 1992) and be able to explain what happened, interpret what is happening, and

predict what will happen (Glaser, 1978). The substantive theory generated in this study does work because it does explain and interpret the experience of the participants. It also predicts what will (or may) happen when an individual from the initial phase progresses through the other two phases.

Relevance is missed when preconceptions or preconceived theories are allowed to force the data into certain categories. "Grounded theory arrives at relevance because it allows core problems and processes to emerge" (Glaser, 1978, p. 5). According to Glaser (1992), when a grounded theory has fit and at the same time it works, then it has achieved relevance. Therefore, the researcher's theory of integration in women living with CD does meet the relevance criterion for grounded theory.

Modifiability is the last evaluative criterion for a grounded theory. The grounded theory should be readily modifiable when new data present variations in emergent properties and categories. The theory is neither verified, nor thrown out, it is modified to accommodate by integration the new concepts" (Glaser, 1992, p. 15). Glaser stated that "good grounded theory should be readily modifiable to new conditions, new subjects and perspectives on the same problem, provided that the same problem is relevant in the new area" (p. 24). As theory was generated, it was necessary to modify properties or categories, that is, as new data were collected, there were new variations that were discovered in the properties or categories. Hernandez' (1991, 1995, 1996; Hernandez et al., 1997; Hernandez et al., 1999) theory of integration was modified to fit the experience of these women living with CD. For example, the lifeway of personifying CD as if it were a separate entity, emerged in the having CD phase; this lifeway readily fit within the having CD phase because it, like other lifeways such as denying, normalizing and minimizing, had the focus of striving to feel or be normal. Also, to describe the experience of women living with CD, having diabetes was changed to having CD for the naming of the first phase of integration. However as stated in the study limitations, further research (additional theoretical sampling) is necessary to saturate the theoretical categories and their properties. It may be that

there will be additional similarities with Hernandez' theory of integration or additional categories and their properties which will need to be added to accommodate these new data. The theory of integration (Hernandez, 1991, 1995, 1996, Hernandez et al., 1997; Hernandez et al., 1999) was found to be *relevant* to the women in this study with CD because it *worked* and it *fit* but required *modification* in order to explain the experience of living with CD as described by the women in this study.

Lincoln and Guba's Trustworthy Criteria

Lincoln and Guba (1985) stated that qualitative research should be evaluated for trustworthiness as reliability and validity are useful measures of rigor only for quantitative research. The four criteria that Lincoln and Guba list to measure trustworthiness include credibility, transferability, dependability, and confirmability.

Credibility refers to the extent of which findings are truly congruent with a person's experience. It is essential that the researcher report the findings described by the participants as clearly as possible. Methods to ensure credibility included attempts to bracket the researcher's preconceptions and prolonged engagement with each participant. Preassumptions were listed and the researcher attempted to keep these at bay during analysis although this did prove to be a very difficult and frustrating task. The thesis advisor helped to point out preassumptions and encouraged the researcher to remove the health care professional blinders obscuring certain areas described by participants during analysis and write-up of the theory. Interviewing the participants three or four times over a period of many months provided the prolonged engagement that allowed the researcher to check her understanding of some of the participants' comments and to more clearly understand their experiences.

Transferability refers to whether or not findings of this study can be applied to other situations. The findings of this study resulted in thick, rich description especially in the having CD phase so that others with CD can see if it applies to their own experiences. Transferability was promoted by writing the substantive theory as clearly as possible and illustrating this conceptual writing with quotes from the participants. This strategy will allow other individuals

with CD to determine whether or not the substantive theory fits their experiences of living with CD.

Dependability refers to the ability of other researchers to arrive at the same conclusions using the same data collection methodology. The participants' experiences were described and an audit trail of direct quotes was maintained through audiotaping, verbatim transcription of all interviews, field notes, memos, and summaries of personal notes. Another researcher could listen to the audiotapes and review the transcripts to arrive at fairly similar conclusions about the substantive theory. Several quotes to illustrate each of the major concepts have been included in the previous chapter to show the reader how grounded theory concepts were derived.

Confirmability or neutrality is when information is objective and free of bias (Lincoln & Guba, 1985). All memos, notes, transcripts, and audiotapes were kept for verification to help ensure confirmability. Aiming for objectivity was attempted by trying to hold preassumptions at bay, however interview questions were found to be sometimes too directive and leading and as a result were somewhat biased. This made it difficult to maintain neutrality. Extensive literature review was avoided until the theory began to evolve in order to decrease biases and preconceptions. However, the researcher had read extensively in the area of CD because of her expertise and involvement in this area. Frequently, concepts in the literature impacted on how she read the data. The use of a content expert and the committee advising the researcher on this thesis enhanced confirmability.

The goal of this study was to discover and gain insights into the unique experience of living with CD from a woman's perspective. The results of this grounded theory study provided an insider's view and a woman's perspective on what it is like to live with CD. It was also verified that Hernandez' (1991, 1995, 1996; Hernandez et al., 1997; Hernandez et al., 1999) theory of integration had relevance to this population.

Implications of Study for Advanced Practice Nurses

The results of studies such as this one help the advanced practice nurse (APN) develop an understanding of what it is like to live with CD. The common experience of four women with CD

does not mean that all women with CD, or men with CD, or even adolescents with CD will have identical experiences. However, if additional research verifies the theory of integration in CD, then there are some major implications for the APN. It is very likely that the APN will encounter more and more women with CD over the course of his/her career given the increase in incidence and the chronic nature of CD. The APN is in an optimal position to be an advocate, educator, advisor and counsellor for clients with CD and to suggest appropriate referrals to other health care disciplines as needed.

For the APN in a clinical specialist role, recognizing that individuals with CD go through a three-phase process of integration would facilitate understanding of individual responses in living with CD. Identification of the phase or the lifeways being used by individuals would be beneficial for the advanced practice nurse in order to develop interventions to meet the particular needs of the individuals. Realizing that individuals in the first phase of CD tend to use denying, normalizing, minimizing and personifying would alert the APN when obtaining a complete history to really listen to the client's concerns and to follow up on symptoms that do not seem to be responding to treatment despite claims from the individual that symptoms are minimal and not impacting their lives. Open, genuine communication and active listening, would be welcoming to women who are in the all phases of integration. The APN, using a collaborative approach with those individuals in the science of one phase, would recognize them as co-experts in CD because of the expertise they have developed related to knowing their particular body responses to CD and knowing what to do about these responses. As the APN and client work together as co-experts, the APN becomes more helpful in assisting clients with their concerns. The APN should realize that clients in this phase of integration would want to engage in activities that will help them to live according to their lifestyle preferences.

An understanding of the theory of integration in CD is essential knowledge for the APN who is an educator. It is important to recognize that individuals in the first phase who are denying, normalizing, minimizing and personifying may not be candidates for an extensive

education program. Clients in this phase may resist learning or may not attend education programs. Explanations should be kept simple and straightforward because they may not be ready for or interested in learning about CD. Clients found to be in the second and third phase of integration may require access to more sources of information such as teaching booklets, internet sites and support groups, and would benefit from referrals to other disciplines such as enterostomal therapists, dietitians and pharmacists and even alternative therapists in order to help find answers and meaning for body cues and patterns. Clients in this third phase may initiate their own education process or contact with others in the health care system to seek the information or assistance they desire. Education of clients and families with CD can promote positive client outcomes and even facilitate the process of integration by focusing on the unique needs of the individual.

The APN who teaches nursing students and other health care disciplines, by sharing results from studies such as these, could increase awareness that living with chronic illnesses such as CD involves complex processes and, as a result, individuals could exhibit very different responses in learning to live with the impact of illness in every day living. By reinforcing the fact that individuals go through phases of integration in living with CD, the APN would also encourage students to use individualized approaches based on identifying and meeting the specific needs of individuals with CD. Curriculum for nursing education and continuing education programs for nurses need to include the dissemination of research studies and findings to enhance the care provided to patients with CD or to patients with other chronic illnesses.

For advanced practice nurses in an administrative role, prevention of hospitalization or decreasing health care usage could be accomplished through the use of ambulatory clinics where CD patients could be seen on a regular basis in a clinic setting. Understanding phases that individuals go through in learning to live with CD would help the APN to establish a clinic that would meet individual needs and provide appropriate referrals. The APN could take a leadership role in transforming and enhancing the care of those with CD by being visionary and anticipating

future directions of health care practice in a growing chronically ill population. Early treatment and intervention for patients with CD could potentially help to avoid the need for costly hospitalization and complex or expensive medications.

Further studies are required by the APN as a researcher to get at the experience of individuals living with CD from their perspective in order to identify strategies and outcomes that are meaningful. More research is needed to determine effective strategies in working with those individuals who are in the having CD phase using the lifeways of denying, normalizing, minimizing and personifying. More research is needed to explore the turning point phase in clients with CD. Knowledge of the process of integration in CD as well as the science of one phase and collaboration with the client as co-expert would help the APN to develop nursing interventions that foster and facilitate ongoing integration.

Conclusions

This study provided an understanding of how CD is perceived and incorporated into the lives of those living with CD. The findings of this study verified that Hernandez' theory of integration (1991, 1995, 1996; Hernandez et al., 1997; Hernandez et al., 1999) applied to women living with CD and was useful in explaining the phases that these participants went through in learning to live with CD. Limitations of the study included 1) researcher driven limitations such as inexperience with the grounded theory methodology, the struggle with preconceptions and failure to theoretical sample to the point of saturation of the theoretical categories, and 2) research design limitations that included the small sample size and the fact that the study involved only adults who were women.

The findings of this study have major implications for advanced practice nurses in education, research, administration and practice by providing an increased understanding of the three phases that individuals go through in the process of integrating the CD and personal selves. Understanding CD from the individual's perspective can provide the APN with a unique insight into what living with CD is like as well as help establish an individualized plan of care including

interventions that are aimed at effective outcomes to meet needs in each phase of integration.

Comparing the results of this study to related research and disseminating the findings of this study are essential strategies for the APN to help build on the knowledge base of the experience of living with CD. More research is needed to explore and confirm the study findings, however, the theory of integration in CD does have potential for use by the APN to improve physical health and quality of life of individuals with CD.

APPENDIX A

INTERVIEW QUESTIONS

1. Tell me what it is like to live with CD now that you have had it for --- years.
2. Could you describe what a normal day is like for you?
3. What were you feeling like before you were diagnosed with CD?
4. Tell me more about your experience in the hospital?
5. You said...I wonder if you could tell me what that means?
6. Describe the perfect health care provider. How could they be most helpful to you?
7. What do you think others need to know about CD?
8. Is there anything you can tell me that would help someone like me who doesn't have CD, understand exactly what having CD is like?

APPENDIX B

INFORMATION and CONSENT FORM

My name is Lynne Compton. I am currently a Master's of Nursing candidate at the University of Windsor. The purpose of my thesis research is to explore the experience of women living with Crohn's disease. This information will increase the knowledge of those in the health care field working with IBD clients. Hopefully, findings will also improve the nursing care provided to women with Crohn's disease.

In order to participate in this research, I will ask you to be interviewed for a minimum of two hours on at least two occasions. The interviews will be conducted at a time and place that is mutually convenient. During the interviews, you will be asked questions relating to living with Crohn's disease from your point of view.

Your participation is completely voluntary and you are free to withdraw from the study at any time without explanation if you so desire. If you have any questions about this research, you may contact the University of Windsor, Office of Research Services, 253- 4232, ext 3916. Confidentiality will be maintained through the use of code names. At no time will you be identified by your real name. Information from the files will be restricted for my viewing only and will be secured in a locked drawer. The information collected may also be published in a research article but at no time will you be identified by name.

If you are interested in participating in this research, please contact me, Lynne Compton at 351-1035 before January 15, 2000 to set up a meeting time. I will explain the study and answer any questions you might have and I will ask you to sign the following consent form. Thank you so much and I look forward to meeting you.

I _____ agree to be interviewed for research purposes by Lynne Compton. I understand that all information will be held strictly confidential and that I will not be named at any time except by a code name. I understand that my decision to participate is completely voluntary and that I am free to withdraw without explanation at any time. I understand the findings of the study will be available upon my request.

Participant signature

Date

Witness

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